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## Disability and Poverty: the need for a more nuanced understanding of implications for development policy and practice

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T: +44 (0)20 3108 3146 F: +44 (0)20 3108 3167 Disability and Poverty: the need for a more nuanced understanding of implications for development policy and practice

NORA GROCE, MARIA KETT, RAYMOND LANG AND JEAN-FRANCOIS TRANI

ABSTRACT The international development community is beginning to recognise that people with disabilities constitute among the poorest and most vulnerable of all groups and thus must be a core issue in development policies and programmes. Yet, the relationship between disability and poverty remains ill-defined and under-researched, with few studies providing robust and verifiable data that examines the intricacies of this relationship. A second, linked issue is the need for – and current lack of – criteria to assess whether and how disability-specific and disability 'mainstreamed' or 'inclusive' programmes work in combating the exclusion, marginalisation and poverty of people with disabilities. This article reviews existing knowledge and theory regarding the disability/poverty nexus. Using both established theoretical constructs and field based data, it attempts to identify what knowledge gaps exist and need to be addressed with future research.

The article also discusses some of the inherent challenges in developing appropriate and effective indicators by which disability issues in poverty alleviation initiatives might be evaluated. These include the need to understand the implications of the poverty/disability nexus not just at the individual, but also at the household and community level. Moreover, there is a need to understand the links between disability and poverty not simply at one point in time, but as an evolving concern over the course of an individual's lifetime – and as something that may in fact, have implication over several generations. Finally, what becomes of impoverished people with disabilities when other members of their communities begin to benefit from successful international development efforts? Do their lives improve as part of

general social and economic advancements even if they have been left out of advances in education, economics and civil society, or are they left increasingly further behind?

We cannot hope to answer all of these questions, given the limited body of data now available to researchers, but by raising them, we hope to move forward the emerging discourse on disability and poverty needed by researchers, donor agencies and development practitioners in ensuring that future policy and practice genuinely meet the needs of people with disabilities in developing countries. Such a discussion is timely, as serious consideration is now being given to the current and future architecture of the international aid paradigms in light of the 2010 review of the Millennium Development Goals.

#### Disability and development in context

Over the past decade, it has become increasingly recognised that disability is an important issue in poverty reduction and poverty alleviation efforts. Partial success has been achieved in this endeavour, but it is readily acknowledged that there is still a long way to go. The close relationship between disability and poverty has long been recognised: Coleridge, in his seminal book, *Disability, Liberation and Development*, stated that: 'disability creates and exasperates poverty by increasing isolation and economic strain, not just for the individual but for the family: there is little doubt that disabled people are among the poorest in poor countries'. However, a great deal of the evidence used to support these assertions remains anecdotal and the complex relationships that exist between poverty and disability remain ill-defined and under-researched, particularly the inter-relational dynamics that exist between the causal factors driving this disability/poverty nexus. This can be attributed to a number of distinct yet interrelated factors. These include lack of a universally agreed global definition of what constitutes disability, and a lack of robust statistical data regarding the social and economic status of people with disabilities, particularly in the global South.

This article reviews the current literature with regard to poverty and disability (particularly in the context of developing countries), building upon earlier work where the contours of the debate were outlined, iii as well as country-specific studies presented utilising the capabilities approach with a view to suggesting avenues for further research.

Here we consider what is known about the causal relationships between poverty and disability, and the impact of poverty on the livelihoods of persons with disabilities<sup>v</sup> in the specific areas of education, health, employment and social protection. Additionally some of the inherent challenges in measuring the impact of poverty and disability are discussed as well as the lack of robust data regarding disability prevalence rates in developing countries. Finally, we acknowledge the lack of efficient and effective implementation modalities for people with disabilities particularly in access to international aid and the lack of political will among politicians and senior government officials in implementing disability-specific and genuinely 'mainstream' (disability inclusive) public services. The article concludes by discussing some of the implications of implementing genuinely inclusive policies, programmes and development initiatives and by making recommendations for further research.

#### Growing attention to the disability/poverty nexus

The rise of the political profile of disability issues within international development is attributable to a series of related factors, not least being the United Nations Convention on the Rights of Persons with Disabilities (CRPD)<sup>vi</sup>, which came into force May 2008. Article 32 (International Cooperation) of the Convention explicitly states that:

States parties recognise the importance of international cooperation in the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with international and regional organisations and civil society, in particular organisations of persons with disabilities.

Furthermore, Article 31 of the CRPD explicitly recognises the fundamental need for more robust statistical data. The Article states that 'States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.' Thus, sovereign states that have ratified the CRPD are legally obligated to ensure that their national policies are inclusive and government organisations are charged with collecting data to monitor progress towards this goal.

In light of the passage of the CRPD, the international disability movement and its allies have been influential in lobbying the United Nations to explicitly address disability vis-à-vis the inclusion of persons with disabilities in MDG initiatives and monitoring and evaluation efforts, arguing that the Millennium Development Goal targets will not be achieved by 2015 unless disability issues are explicitly addressed.<sup>vii</sup>

The combined forces of the CRPD and the Millennium Development Goals provide a powerful foundation on which to build momentum for the inclusion of disability in development. Yet reframing laws and policies to comply with these new driving factors constitutes only a first step. In many countries, progressive human rights-based policies and programmes for persons with disabilities exist on paper, but are honoured in the breach, without adequate infrastructures to ensure their effective implementation and enforcement.

Furthermore, sovereign states that have ratified the CRPD have the option of 'progressive implementation', whereby governments are allowed to implement the Convention's Articles over a number of years.

#### Current knowledge about the disability/poverty nexus

There is strong anecdotal evidence to suggest that disability and poverty are highly correlated, with the often quoted statement that each are 'a cause and a consequence of the other.' However, as Braithwaite and Mont have noted, 'the relationship between poverty and disability is not well established in the literature'. Lack of definitional clarity, robust statistics and limited attention to or funding for disability research as a routine component of international development has resulted in a fragile evidence base for the stated links between disability and poverty. A recent critical review of the available peer reviewed literature on disability and poverty in both the international development and global disability literatures has found that of the 293 articles on disability and poverty identified in the literature search, only 27 (9.3 per cent) were evidence based.\*

Over the past several years, however, a small but growing body of research has gone beyond broad general statements about the links between poverty and disability to provide specificity. The increasing number of such studies reflects an evolving sophistication in research and methodology on disability and poverty issues.

For example, new data is beginning to clearly show that persons with disabilities in low and middle-income countries are poorer than their non-disabled peers in terms of access to education, access to health care, employment, income, social support and civic involvement. Mitra and Sambamoorthi find in the case of the rural labour market in India that men with disabilities received lower wages than non-disabled counterparts, after controlling for a series

of socioeconomic factors.xi Comparing data from household surveys in 14 developing countries, Filmer finds that disability is associated with an increased probability of individuals falling into the poorest of the poor group.xii Braithwaite and Mont studying the disability-poverty link also find a relationship between poverty and disability, although significantly, they note that based on the currently available data, the evidence base for this assumption is still weak. XIII Trani and Loeb building on this body of data and reviewing evidence from Afghanistan and Zambia find a link between disability and poverty, but raise the important point that the link between disability and poverty reflects complex and interdependent relationships - concluding that such poverty is more multidimensional and nuanced than we have previously thought.xiv It is also true that economic conditions and the economic status of individuals and households may change over time. Researchers are beginning to identify the need for longitudinal surveys to explore these changes.<sup>xv</sup> Various cross-sectional surveys on different samples at different points in time would allow comparison of global changes in poverty rates, although these types of studies do not provide information about the evolution of aggregates within specific households. These bodies of research can be broadly divided into two groups: why disability accentuates poverty and why poverty increases the likelihood of disability.

#### Why disability accentuates poverty

Identification of who is poor has been a central issue for poverty alleviation policies and programmes. Long standing assumptions by economists which consider those individuals as poor whose income falls below a reference subsistence level called the poverty line, have given way to poverty increasingly being considered a multidimensional issue beyond insufficiency of income or consumption levels.

Sen demonstrating the limitations attached to traditional poverty measures, such as the head count ratio and the income gap ratio, argues that poverty can be defined by a lack of well-being. \*\*vi\* Sen further argues that it is important to consider the distribution of income among the poor and the change in total poverty induced by a worsening of the situation of people already poor. Over the past decades a growing number of authors have further argued that poverty cannot be measured by a single indicator of well-being but must also take into consideration 'multiple' dimensions of poverty, such as food intake, shelter, life expectancy, education, and provision of public goods. \*\*xviii\*\* Recent theoretical approaches on the nature of chronic poverty increasingly are based on this multidimensional concept of poverty. The basic needs approach for example, considers poverty as not only a deprivation of income but also as an insufficient coverage of various human needs. \*\*xviii\*\* Sen identifies poverty as a deprivation of capabilities.\*\*

Thinking of poverty in various dimensions raises another question: are the poor those deprived on any dimension? Or to be designated as poor does an individual have to be deprived on all dimensions? Alkire and Foster have introduced a method to identify the poor based on two forms of cut-off.xx The first cut-off identifies on each dimension if a person is poor or not. The second cut-off identifies the number of dimensions on which a person is identified as poor in a given context. A minimum of dimensions of deprivation is then established to identify the multidimensional poor in order to better facilitate the targeting of public policies. In the context of Afghanistan, Trani et al have shown, applying the Alkire and Foster methodology, that children with disability were more deprived at all ages than non-disabled children, and were more severely deprived and in a higher number of dimensions.xxi Compounding this, in both Western and developing countries, the cost of living associated with having an impairment/disability is likely to be greater for persons with disabilities than their non-disabled counterparts.xxii

Yeo and Moore argue more generally that people with disabilities are more likely to be poor, due to the systemic institutional, environmental and attitudinal barriers encountered in their daily lives, which in turn results in their entrenched social exclusion and their lack of participation in contemporary society. There are ramifications on all levels: social marginalisation and isolation, lack of access to education, adequate housing, enough nutritious food and clean water and basic sanitation, lack of access to health care, credit and lack of ability to participate fully in legal and political processes. A key component is the lack of preparation for and meaningful inclusion in the workforce.

Compounding this are the broader issues of environmental discrimination in which the physical environment is inaccessible; for example, being unable to access public transport systems which Imire poignantly argues inevitably results in 'apartheid by design' and institutional discrimination which can be manifested through the systemic exclusion and marginalisation of people with disabilities from participating in developing poverty reduction strategies. \*\*xxvii\*\*

Such lack of access has repercussions throughout the life course of a person with a disability, as well as for their nuclear and extended families. Take for example, education. The lack of access to education for children with disabilities has repercussions throughout the lifespan. Approximately one-third of the 72 million primary school aged children currently out of school worldwide have disabilities. A World Bank Study in India found that disability is a stronger correlate to non-enrolment than gender or class. A study of living conditions of people with disabilities in Namibia found that twice as many disabled members of households had never attended school as non-disabled members. Another study in Uganda found that children living in households with disabled family members are less likely to

attend school.<sup>xxxi</sup> In Honduras, 51 per cent of people with disabilities are illiterate, compared to 19 per cent of the general population.<sup>xxxii</sup> The economic implications for these children as they grow into adulthood are profound. The links between illiteracy or marginal literacy and poverty are well established and the lack of education for children significantly increases the likelihood that they will raise their own children in poverty.<sup>xxxiii</sup>

#### Why poverty increases the likelihood of disability

It is also the case that those who live in a state of chronic poverty are more likely to have a disability. Chronically poor people are often at risk of ill health and injuries which may lead to disability through a number of routes. They often live in unsanitary and substandard housing conditions, are unable to afford nutritious foods, lack the ability to access clean water and basic sanitation, are more likely to have unsafe or dangerous jobs, and live in areas where there is a higher probability that they will be victims of violence. And should they become ill or injured, these already poor people are also less likely to be able to afford the medical care that would keep an illness or injury from becoming a permanent disability. These poverty-related environmental and structural risks for disability mean that the poor who become disabled will descend further into poverty. This will have a significant effect not only on individuals, but upon entire households.

The Chronic Poverty Research Centre, in its 2008-09 global report entitled *Eclipsing Poverty Traps*, states that:

The chronically poor are commonly deprived across multiple dimensions. Combinations of capability deprivation, low levels of material assets, and socio-political marginality keep them poor for long periods. xxxv

The Chronic Poverty Research Centre delineates principal causes of chronic poverty, all of which resonate with those characteristics that typify the livelihoods of people with disabilities in developing countries. xxxvi

- An insecurity trap: those who live in a constant state of insecurity, because they have very few tangible assets and entitlements, are at increased risk of being susceptible to external shocks. These include economic shocks, political upheavals and environmental and humanitarian disasters (such as an earthquake or a tsunami), or war and civil strife (with these shocks disproportionately affecting the poorest countries). Research has shown that people with disabilities face acute vulnerability to economic crises and political upheavals in the aftermath of civil conflict but are less likely than their non-disabled community members to benefit from interventions or humanitarian assistance put in place in response to these shocks.
- Limited citizenship: those who are currently poor often do not have a political voice with which to explicitly make their needs and aspirations known. Historically, people with disabilities have often been excluded from playing an active part in the political process in their own countries, nor are they key stakeholders in the international development arena. While over the last 30 years disabled peoples' organisations have been established in most countries with the mandate to promote and protect disability rights, they have historically lacked the political or economic clout needed to play central roles in discussions. Ideally, their role will be significantly strengthened by the successful enactment of the CRPD; however, this has yet to be seen.
- Social discrimination: the livelihoods of the 'chronically poor' are often characterised
   by exploitative relationships, and where these traditionally exclusionary social

attitudes prevail, this reinforces their social exclusion from society. Similarly, people with disabilities often encounter negative social attitudes held by government officials, policy makers, people in their communities and even members of their own family.

• Poor work opportunities: those who are chronically poor often find it extremely hard to secure long-term sustainable employment, which is often exacerbated by poor health status and the lack of formal educational qualifications. Likewise, the large majority of people with disabilities are either unemployed or under-employed.xxxviii This is found in both developed and developing countries. For example, Mitra and Sambamoorthixxxiix reported an overall gap in employment rates between people with and without disabilities explained by productivity limitation and discrimination through stigma in Pudukottai, a rural district of Tamil Nadu, in southern India, although interestingly, these authors did not find wage differences in this particular study. Trani and Loeb found that people with disabilities in Afghanistan and Zambia experienced significantly more difficulty in accessing employment.xl This relationship was stronger for people with cognitive disabilities, mental illnesses or multiple disabilities who are less likely than other disabled persons to access the labour market.

#### Systemic challenges to analysing disability and poverty

Our ability to understand the links between disability and poverty is further hampered by the nature of the data available. Even the most basic of issues – defining disability to allow a body of data to begin to be assembled – is problematic. Indeed, during the negotiation process of the CRPD, despite concerted efforts, it was not possible to agree on any one definition. This is explicitly recognised within the Convention itself, which in the preamble states:

That disability is an evolving concept and that disability results from the interaction within persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.<sup>xlii</sup>

Unlike an arena such as gender, where at least data can be assembled based on number of women in a population, currently there is no universally agreed global definition of what constitutes 'disability'. Instead, the number of people living with a disability observed in any population also largely depends on the model (medical, social, biosocial model) adopted to define disability and the goals pursued (for instance implementing disability focused welfare politics or compiling census data).

In the past 20 years, several international initiatives to do such enumeration have emerged. The two most prominent are the WHO's International Classification of Functioning, Disability and Health (ICF) and the work of the United Nations' Washington Group. The ICF was developed by the World Health Organization as a basis for determining disability prevalence rates and disability-specific entitlements. The Despite its revision in 2001, which gave greater recognition to the impact of environmental and structural factors vis-à-vis disability, the use of the ICF and other research methodologies that have primarily focused on impairment have been severely criticised by prominent members of the disability movement, in the belief that it does not really analyse exclusion and discrimination of people with disabilities. The set of questions developed by the Washington Group and now being piloted and refined, also holds promise in helping to identify who is disabled within a household or community, but the questions are being designed for use in censuses and do not immediately reflect more complex issues such as access to education, employment, health and other concerns that may

make a difference in the disability/poverty nexus. While the two systems are often used in tandem, the ICF system evaluates an individual's ability to function with a disability within a social matrix and the Washington Group is primarily intended as a way to identify disability for census takers and others seeking to enumerate persons with disabilities in a population. Their purposes often cross but they are not identical. Currently, there is not an 'exclusive' or 'single' measure of disability.

Lack of a consistently used definition of disability has ramifications in many arenas but none more so than in the ability to discuss the links between disability and poverty, where it is very difficult to undertake any comparative analysis of disability and poverty between or even within countries. And these debates regarding how disability is defined are not exclusively of academic interest, but are fundamental to understanding issues of how to reduce poverty among persons with disabilities and their families. Numbers and statistics for good or ill, are the current 'lingua franca' of international development. If a straightforward estimate of the number of persons with disabilities is not available, or if this population cannot be monitored and evaluated in conjunction with broad economic development efforts, then policy makers and practitioners are more likely to put disability aside while they address seemingly more clear cut, familiar issues.

Moreover, the mere 'counting' of persons with disabilities (thereby calculating a disability prevalence rate) is a blunt instrument in terms of developing and monitoring the impact of genuinely inclusive policies and services that might enhance the livelihoods of persons with disabilities. Efforts to understand the links between disability and poverty cannot stop there. The lack of both qualitative and quantitative data sources, the few combined studies that bring together qualitative and quantitative methodologies to answer basic questions, the constraints of framing issues by discipline rather than approaching complex questions

through multidisciplinary methodologies and the lack of much longitudinal research that allows us to say little about persons living with disabilities over time, all limit our ability to understand the disability/poverty nexus in as much depth as such a pressing question demands.

What is required are more nuanced understandings of the actual experience of living with a disability within a specific country, taking into account political, economic, social and cultural complexities. Reports such as SINTEF's national surveys of disability (Namibia, Malawi and South Africa), xlvii and the UK Department for International Development's Disability Scoping Studies in Africa<sup>xlviii</sup> are beginning to fill in this picture. For example, in SINTEF's Representative National Survey of People with Activity Limitations in Namibia it was found that employment for people with disabilities was higher in urban areas. xlix Households with disabled family members had a lower mean income, combined with less mean expenses regardless of seasonal fluctuations. Furthermore, households with a disabled family member, on average, had fewer possessions compared with households without disabled members. Fewer disabled households stated that salaried work was their primary source of income (24 per cent versus 40 per cent), and this reflected the fact that fewer households with disabled family members had someone working. Slightly more disabled households received their family income from cash cropping and subsistence farming, while 6 per cent of all such households stated that the disability grant was their primary source of family income. This Namibian case study provides a good example of how more information than income alone can be of use in providing an enriched description of the complex livelihoods and economic status of people with disabilities.

#### Multidimensional poverty and disability

What then can be said regarding the links between disability and poverty? In fact, a small but growing body of data points to a series of interesting issues that may allow more nuanced approaches to disentangling disability and poverty issues, allowing more precise targeting of groups and subgroups within the disability community for poverty alleviation efforts. For a start, it is increasingly clear that the links between disability and poverty are multidimensional in nature. Poverty cannot be understood only in terms of deprivation of income.

For example, Trani and Loeb, reviewing data for Afghanistan and Zambia, using Sen's capability approach as a foundational concept, found evidence of lower basic capabilities (access to health care, education and employment) for people with disabilities, whatever their disability status; however, income poverty measured by an asset index was not statistically different between people with and without disabilities. This means that income poverty in countries that rate very low on international indicators (Afghanistan and Zambia are among the lowest ranking on UNDP's Human Development Index) is not the most critical discriminatory factor between disabled and non-disabled individuals. Rather it may be that there is inequality of access to basic capabilities linked to that disability status.

Nussbaum defines these as 'central human capabilities' and argues that they have an impact of real poverty: poverty is the impossibility for individuals to be and do what they value due to lack of opportunities. Persons with disabilities can be particularly deprived since disability, due to prejudice, physical barriers and other constraints, can reduce the ability to earn an income. Conversely, a person with disabilities might need a higher income to achieve the same level of functioning as a non-disabled person. As a result, with a same income as non-disabled people, persons with disabilities might face a capability failure. Injustice and

inequality result from this inability to have the same options and opportunities as all other members of society.<sup>lii</sup>

#### Poverty and individual compounding factors

Poverty is not experienced uniformly by persons with disabilities, but is mediated through a number of compounding factors. For example, persons living with different types of impairments, even within the same community may face different constraints linked to poverty. So while 'lack of education' as a contributory factor of poverty among persons with disabilities is routinely referenced, Table 1 shows significant differences in access to school in Afghanistan for children between seven and fifteen years old according to the type of disability. Results show that children with sensory and mental disabilities are far less likely to access education than either non-disabled *or* physically disabled children.

#### [insert Table 1]

Factors include not just the type of disability but the age at which it is acquired, whether one is male or female, whether one lives in a rural or urban setting, and whether one is a member of an ethnic or minority community that has less access to resources from the national government or local community. All these have implications for poverty throughout one's life time. Based on a measure of multidimensional poverty associating 10 dimensions or domains (health; love and care; family assets; food security; social inclusion; education; freedom from economic and non-economic exploitation and leisure activities; shelter and environment; personal autonomy; mobility), Trani, Biggeri and Mauro analysing data from Afghanistan found that disabled children in rural areas are more deprived on various dimensions than disabled children in urban areas; disabled children are more deprived than non-disabled children at all ages; and girls with disabilities are more deprived on all

dimensions than boys with or without disabilities.<sup>liii</sup> We have long known or suspected many of these issues will be deciding factors in whether a disabled individual lives in poverty, but this growing body of evidence-based research is now better illuminating these links.

#### **Understanding poverty at the household level**

Intriguingly there is another, growing body of research that is beginning to show that these links between poverty and disability extend beyond the individual through studies of poverty and disability at the household level. This is of particular importance in traditional societies where all people – including all persons with disabilities – live in extended families and poverty is shared by all members of the family.

Studies are beginning to illuminate the mechanism through which households are affected economically by having one or more members living with a disability. For example in a study from Kenya, Ingstad and Grut show the detrimental effects at the household level on poor families living with a disabled child. Similar findings are reported from Yemen by Grut and Ingstad in what the authors describe as a 'vicious circle existing between having a disabled child and remaining in or falling further into poverty'. Erb and Harriss-White's social anthropological study of disability in three villages in Tamil Nadu, South India, show that there were three categories of costs associated with disability at the household level. First, direct costs attributed to such factors as the need for medical treatment, including travel costs. Second, the opportunity cost related to income forgone as a direct result of this disability. Third, indirect costs associated with the provision of 'care', either provided by family members or from members of the local community. The magnitude of these costs were substantial, with direct costs equal to as much as three months' income of non-disabled agricultural households. In Tanzania, survey data showed that households with a disabled member have a mean consumption of less than 60 per cent of the average and include 20 per

cent more members than average. Viiii The link between disability and poverty at the household level was also found in Poland where Hoopengardner found disability was likelier in lower-income households and disability increased the likelihood of having a lower income. Iix Importantly, these findings show that the root cause of the problem is not the person with a disability, but the social marginalisation, and lack of access to basic resources such as education, employment, health care and social support systems that link disability and poverty at the household level.

Employment is another arena in which the interaction between the individual and the household in which he or she lives may also have significant implications for poverty. Much of the discussion of disability and poverty until recently has focused on income generation by persons with disabilities through jobs in the formal sector where unemployment rates for persons with disabilities worldwide reach above 80 per cent. lx However the vast majority of all people – including people with disabilities in developing countries – do not have formal jobs but rather are self-employed. lxi Such employment, while common, has the associated challenges of job insecurity, lack of pension and other welfare benefits, such as unemployment benefits if times get hard. For those who are self-employed, the lack of education and skills training is a further limitation to rising out of poverty, as is lack of equal access to micro-credit and other finance schemes. lxii Compounding this are issues of stigma and prejudice towards people with disabilities that frequently keep customers from calling upon their service. (For example, in southern Africa, one of the most common ways of making a living for poor women with little education is preparing food to sell on the streets, but customers will not buy food from women with epilepsy, fearing that it is an infectious condition.) Furthermore, millions of persons with disabilities who are unable to find any paid work support themselves or contribute to their households by doing unpaid labour – caring for family members, helping on a family farm or in a family shop – or otherwise take on jobs

that make economic contributions but are rarely tracked in studies of either the formal *or* informal economy.

Furthermore, for many persons with disabilities around the world, should they earn money or receive goods or services in exchange for their work, these 'wages' are not theirs to allocate, but rather are paid directly to a non-disabled family member or another who decides when and how such funds are spent. Such arrangements are common when it is believed that persons with disabilities are not entitled to or not considered able to make financial decisions for themselves. The issue then becomes not simply how much a person with disability earns that enables him or her to become less poor but the right this person has to determine how such money is distributed within the family and household in which he or she lives.

Nor are these the only issues. At the household level, costs associated with medical interventions in the wake of an individual born with a disability or becoming disabled through illness or accident might be considerable. Lower earning potential of both the individual and immediate family members who may be called upon to provide part-time or full-time care will have a significant impact on the household. Largely unexplored, but of significant concern is the cross-generational impact of disability on a household over time. For example, in many cases where a member of the family, particularly the primary breadwinner, becomes disabled, families meet mounting costs by first reducing less necessary expenses, then cutting back on necessary expenses, such as food, and beginning to sell whatever assets they have. Often they first part with farm animals, jewellery or other cherished possessions, but eventually also begin parting with significant assets, such as tools or land that are necessary to make a living. Parting with ongoing sources of income, such as land, not only further impoverishes the family in the present, but also takes away viable potential sources of income for children and grandchildren. Other long-term consequences of

an individual, particularly a primary breadwinner, becoming disabled can be anticipated. For example, in societies where there are few economic options or economic support systems for those with disability, the slide into poverty for many families means that children will be taken out of school to help provide care or to make up lost income. This has economic repercussions for that child's earning potential as an adult and for that child's own children as well.

#### The role of monetary income in poverty alleviation

While acknowledging that it is important to conceptualise poverty within a multidimensional framework, it is nevertheless critical to also discuss the role played by monetary income for people with disabilities. Within the academic literature, there is increasing debate regarding what are the most appropriate monetary mechanisms available to assist persons with disabilities. These include micro-finance, micro-credit, saving schemes, apprenticeships and insurance schemes. The United Nations has estimated that the majority of people with disabilities who are employed work in the informal sector, with the vast majority self-employed. This raises the importance of providing sufficient working capital to ensure that their businesses are sustainable. What is known is that one of the most effective mechanisms by which people with disabilities are able to access micro-finance is savings schemes, referred to in the literature as Rotating Savings and Credit Associations. These are essentially self-help groups that pool existing resources within the local community, which can then be lent to people with disabilities in order to provide start-up capital or investment for the future exploration of a business. Typically, such schemes comprise 20-30 people, which fosters accountability and transparency in the making of loans.

Most micro-finance institutions (MFIs) claim to have a double bottom line - reaching both financial and social objectives, yet many avoid clients with disabilities. People with

disabilities constitute less than 1 per cent of clients for most MFIs. lxvii Of particular concern, recent studies show that non-disabled community members as well as officials responsible for organising and implementing MFIs are often reluctant to include persons with disabilities in mico-finance schemes, incorrectly assuming that persons with disabilities will be unable to pay back the money borrowed because of lack of skills, ill health and social marginalisation. Martinelli and Mersland identify additional barriers to appropriate financial services and credit, including the lack of confidence among many people with disabilities in their own ability to run their businesses, the inflexible design of existing savings and credit services tailored at the general population, and the asymmetric availability of information regarding micro-finance to persons with disabilities. lxix

Of note, Bwire *et al* report that this exclusion from community MFI schemes can be addressed and changed. Their paper found that larger MFIs in Uganda had an average of 0.65 per cent disabled clients but after participating in a short training course on working with people with disabilities, the same MFIs reported less than a year later that 1 per cent of their clients were disabled – nearly double. This lack of inclusion may also account for the fact that a study by Handicap International found that in the countries reviewed, 83 per cent of disabled people's organisations operated their own credit schemes. While it is encouraging to think that this may reflect growing awareness of the need to address the disability/poverty link, it may also reflect the discouraging lack of inclusion of persons with disabilities in more mainstream community based MFIs.

Another important source of income for people with disabilities is social protection programmes. Research conducted by Gooding and Marriot explored the relative advantages and disadvantages of such programmes. As with micro-finance, social protection embraces a variety of schemes, including cash transfers and government grants. A growing number of

developing countries have cash transfer programmes specifically for people with disabilities. These include Brazil, Chile, Lesotho, Mozambique, Namibia, South Africa, Bangladesh, India and Nepal. The level of allowances varies enormously, and the eligibility criteria are often related to the severity of impairment. Moreover, many countries have mainstream cash transfer programmes for the general population, but there is insufficient evidence to determine to what extent these are utilised by people with disabilities. Gooding and Marriot identified several barriers that impeded people with disabilities from utilising cash transfer programmes to their full potential. These included low levels of funding; complex and unaccountable administrative systems; the physical inaccessibility or unavailability of services; and the limited awareness of the availability of such schemes by persons with disabilities themselves.

Future research needs to consider new and emerging cash transfer schemes and other social support mechanisms beginning to be introduced in countries where no previous programmes existed for those who live in the most extreme poverty. Where such schemes are considered part of a right to a basic quality of life for all citizens, they may have significant implications for raising the economic status of both persons with disabilities and households with disabled members. In countries like South Africa such programmes may help persons with disabilities redefine their economic role because of their ability to bring in money both for themselves and their households. Yet such schemes also raise concerns about how persons with disabilities might be exploited by others because of this new income stream. Ixxiii

Such cash transfer schemes, while still untenable for the poorest countries, are beginning to be part of the economic and political landscapes in middle-income countries such as South Africa and Brazil. This is of particular note because in a recent study, Sumner of the UK's Institute of Development Studies highlights the fact that while in 1990 over 90 per cent of the

world's poor lived in countries with the lowest GDPs, today almost three-quarters of the estimated 1.3 billion people living on less than \$1.25 a day now live in middle-income countries. lxxiv This demographic shift reflects the progress that many developing countries have made in fostering economic growth, but in these countries, this growth is also reflected in a widening margin between the poor and those who are better off. In light of this demographic shift, Sumner concludes that poverty may be turning from an international distribution problem to a national one. How might cash transfer schemes benefit persons with disabilities in such countries? And what social and political capital will be needed through both civil society and government, to make persons with disabilities part of this new economic agenda?

#### A widening gap

Also interestingly, a small but growing group of papers is now finding that when persons with disabilities are living in households and communities facing abject poverty, the resources available to them – food, clothing, education and income – are in fact, not significantly different from the limited access to resources shared by other members of their households. In communities where improving economic conditions, increased access to education, employment and income, health care and credit allow individuals to begin to improve their quality of life, what will happen to persons with disabilities? In communities where persons with disabilities face social marginalisation, lack access to education, employment, health care, legal representation and credit, individuals with disabilities may be at risk of finding themselves more marginalised in a changing economic climate. In such communities, will persons with disabilities fall further behind if their economic position remains fixed while those around them begin to rise out of poverty?

#### Implications for policymakers and development practitioners

The emerging recognition of the complexity of the link between disability and poverty may also explain why this link has been under-researched. Many of the issues raised here are not unique to the disability sector, but rather are indicative of implementing many social and economic policies within challenging environments. Such an enterprise is not exclusively of an academic interest, for bilateral and multilateral donor agencies are grappling with what the most effective policies, strategies and aid modalities are to ensure that future development initiatives are genuinely inclusive.

Reflecting the need for identifying more effective policies and programmes, in recent years, a series of strategy papers and policy documents have been published by bilateral and multilateral donors on their proposed strategies for including disability issues within their core poverty alleviation activities. lxxvi

For example, the UK's Department for International Development (DFID) published its issues paper *Disability, Poverty and Development* in 2000, which advocated the adoption of a twintrack approach to disability and development programming. Ixxvii Under this approach, services and other development initiatives that are specifically targeted to people with disabilities would be implemented, in conjunction with strategies that ensure that people with disabilities are able to access mainstream public services (for example, clean water and basic sanitation or the inclusion of children with disabilities within mainstream schools). More recently, DFID in 2007 published its 'How to note' on disability providing practical guidance to DFID country offices on how to mainstream disability issues in their core activities. The Australian Government has also produced a five-year strategy regarding inclusive development for the period 2009-2014, based on the principles delineated in the CRPD. Ixxix

Encouraging as such efforts are, a critical gap continues to exist – the need to build a disability component into *all aspects* of international development efforts. It is still a rare international development initiative – be it by a UN agency, a bilateral organisation or an NGO – that systematically includes disability in all aspects of all programmes. As noted in the UN Department of Economic and Social Affairs' forthcoming paper on the Millennium Development Goals, simply listing 'persons with disabilities' as one of a number of vulnerable or at-risk groups, while commendable, does not move the agenda forward. Inclusion of persons with disabilities must be a routine part of all programs that address chronic poverty - in programme design and funding, in oversight and implementation and in monitoring and evaluation. The same rigour must be brought into play to make disability issues a component of all efforts to eradicate chronic poverty as is now standard with women and gender issues in poverty alleviation efforts.

In the ideal world, it would be very beneficial to develop global indicators that will critically assess how disability rights, in concert with the effective social inclusion of persons with disabilities can be monitored in all poverty alleviation efforts. However, taking into account the challenges that have been delineated above, this enterprise is by no means an easy task. There are both positive and negative factors that need to be taken into account when developing indicators for the monitoring and evaluation of disability policies and programmes, particularly in relation to poverty alleviation. If robust qualitative and quantitative indicators can be developed, then there is the potential to establish benchmarks and identify standards by which services (provided by national governments, NGOs and bilateral and multilateral donor agencies as well as UN agencies) can be assessed. However, in order for this to be effective, it presupposes that that universal agreement, negotiated by sovereign states and civil society institutions together with donor agencies, can be reached about which indicators should be used.

Of course the concern is that to arrive at a global consensus for indicators, given the above challenges, organisations and donors may only agree on minimum standards. The positive aspects of such efforts would promote inclusion, ensure quality standards and allow for the consistent inclusion of disability issues to ensure that persons with disabilities are part of and benefit by poverty alleviation efforts to the same degree as all other members of society. The United Nations has already developed such a theoretical and methodological framework with indicators for monitoring of human rights and their violations. Any indicators that assess the impact of progressive, rights-based policies and practices to address poverty among persons with disabilities, both at a national level and also in relation to the CRPD, might build existing analytical tools that have been developed.

#### **Conclusions**

In this paper we have discussed how a growing body of literature seems to be leading to an evolving and increasingly sophisticated discussion on the links between disability and poverty.

The issue is not simply to call for more data – although that is surely needed – but also to consider the need for more *nuanced* analysis that reflects the complex world within which poverty among persons with disabilities must be considered. Compounding variables such as age, gender, rural or urban residence and being a member of a specific ethnic or minority community must be taken into consideration. In other words, it is not simply *more* research on the links between disability and poverty that we need, but more research that explores what poverty means at the level of the individual, the household, the community and broader society.

This article has delineated some of the most systemic challenges and obstacles in undertaking rigorous research in the field of disability and poverty. However, it is nevertheless possible to identify some important avenues for future research. This would include the need to develop econometric models that would help analyse the dynamics and causalities that exist between disability and poverty. Such an enterprise would assist in determining which are the most important causal factors driving the disability/poverty nexus. For example, is access to education the most significant catalyst in determining whether a person with a disability is able to achieve long-term, sustainable employment? Or is access to micro-finance a more important factor? While such factors cannot be considered in isolation, such analysis may help identify what issues and approaches may make the greatest difference most efficiently and thus should be given priority. Another potentially fruitful avenue of research would be to undertake a longitudinal analysis of how people with disabilities encounter poverty over the course of their lives. This would involve both quantitative surveys, in combination with indepth ethnographic interviews to explore their experiences of living in a state of chronic poverty. A further area of research would be the development and utilisation of appropriate and effective benchmarks and indicators, particularly in analysing the disability/poverty nexus. Finally, more research is required to investigate interactions between social protection programmes (defined in the broadest sense) and the incentives for people with disabilities to secure sustainable long-term employment.

The increasing awareness that the links between poverty and disability are more complex than originally envisioned should be taken as a reflection of significant progress. Certainly in other fields – for example, gender and poverty studies – understanding the complexity of links between women and poverty has allowed development efforts at all levels to more effectively design and target workable interventions. It can similarly be anticipated that the more we know about the links between disability and poverty, the more effectively we can

intervene to make a difference in the lives of persons with disabilities who today continue to struggle with poverty.

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Throughout this article, the term 'people with disabilities' is used in alignment with its use in the UN Convention on the Rights of Persons with Disabilities.

<sup>&</sup>lt;sup>vi</sup> United Nations Convention on the Rights of Persons with Disabilities, New York, NY: United Nations, 2008, at

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