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Poverty, Disability and Social Exclusion: New Strategies for Achieving Inclusive Development

Connie Laurin-Bowie
Inclusion International

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Poverty, Disability and Social Exclusion: New Strategies for Achieving Inclusive Development

Abstract
[Excerpt] Despite international investments in development initiatives targeted to people who have a disability – investments by domestic governments in support to people who have a disability and commitments by governments to international and domestic human rights commitments – little if any progress has been made in improving the economic, political or social status of people who have a disability in developing countries. To understand why people with disabilities continue to be among the most disadvantaged people in the world we must consider how people with disabilities are perceived by policy makers and how development policy addresses disability. If real progress is to be made in achieving better lives for people with disabilities both the perception of people with disabilities and our policy objectives must change. This paper outlines the need for a shift from disability policy to inclusive development policy and proposes that civil society organizations require expanded strategies to contribute to this shift. The global strategy developed by *Inclusion International* to promote the inclusion of people with intellectual disabilities and their families in the *UN Millennium Development Goals* illustrates what this shift means for an international disability organization and demonstrates how we can "link local voices to global change".

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Poverty, Disability and Social Exclusion: New Strategies for Achieving Inclusive Development

Connie Laurin-Bowie

Despite international investments in development initiatives targeted to people who have a disability – investments by domestic governments in support to people who have a disability and commitments by governments to international and domestic human rights commitments – little if any progress has been made in improving the economic, political or social status of people who have a disability in developing countries. To understand why people with disabilities continue to be among the most disadvantaged people in the world we must consider how people with disabilities are perceived by policy makers and how development policy addresses disability. If real progress is to be made in achieving better lives for people with disabilities both the perception of people with disabilities and our policy objectives must change. This paper outlines the need for a shift from disability policy to inclusive development policy and proposes that civil society organizations require expanded strategies to contribute to this shift. The global strategy developed by *Inclusion International* to promote the inclusion of people with intellectual disabilities and their families in the UN *Millennium Development Goals* illustrates what this shift means for an international disability organization and demonstrates how we can "link local voices to global change".

Disability has traditionally been characterized and diagnosed primarily as a condition requiring medical attention and rehabilitation – an assumption that has led to care and treatment based on treating individual deficits. The widespread creation of specialized and separate services for persons with a disability including special education and vocational training are the legacy of this approach.

A 1997 study commissioned by the *Inter-American Development Bank* indicated service coverage in Central America was less than 3%, between 1.5% and 15% depending on the country. Strategies to create more traditional services cannot achieve significant coverage of people who have a disability particularly in countries where the projected population of people who have a disability is expected to make up the majority of the population (as in some African countries).

Moreover, these services and investments have not proven effective in improving the well being of people who have a disability. Over and over investments in disability initiatives have focused on the provision of therapies or services which are intended to ameliorate the impact of a disability either by preventing the disability; providing rehabilitation, aids or services. There has been less investment in the supports needed for people to participate in the social, economic, political and cultural life of their societies. Even where such supports have been provided, there has been inadequate investment in schools, health care, and child development schemes to ensure they are *designed* to be inclusive.

Few initiatives which have as their objective the inclusion of people who have a disability have focused on changing the systems in which a person with a disability is attempting to participate in – classrooms; work environments; communities, etc. Investments continue to focus almost exclusively on the disability with little or no effort being made to build inclusive systems.

While the disability movement has evolved over time to reflect a human rights approach to disability issues (rejecting the medical model of disability), the international human rights community has become increasingly frustrated by the limited mechanisms available for promoting social change. Many human rights monitoring mechanisms, while useful in raising awareness about human rights abuses, have done little to put in place the institutional and cultural building blocks for societies that are inclusive of all groups. In response to the call for recognition of the human rights of people with disabilities development agencies, governments and international institutions have developed models and approaches to redressing exclusion of persons with disabilities focused on the provision of direct support. The disability human rights agenda has largely been interpreted by policy makers and development agencies as a service provision agenda; developed as a segregated system of disability specific measures that inadvertently contribute to segregation and exclusion. As a result social exclusion of people with disabilities remains the predominate challenge facing advocacy organizations at the domestic and international level.

Much has been made of the *new economy* emerging as information and knowledge capacities that are increasingly becoming a driving force of economic value. Economic globalization is advancing, but with it there is a growing polarization between regions of the world. Societies may be more knowledge-driven, but often it is economic goals driving knowledge and information development rather than social goals. The result is uneven social and economic progress globally. Many civil society groups have pointed to the negative impact of contemporary economic globalization on people who are already

vulnerable, and on regions already struggling with lack of infrastructure, poverty, and economic degradation. This is certainly the case for people who have a disability, for whom the changing structure of economies has the potential to further marginalize and disadvantage.

Given the emerging challenges of a new economy, the limitations of our human rights instruments, and the limitations of current disability related investments in enabling inclusion, what strategies can be used globally to advance the human rights and inclusion of people who have a disability in our societies?

As one of the seven international disability organizations recognized by the United Nations, *Inclusion International* (II) has set out a plan to respond to these challenges and has developed strategies for making a contribution to the global agenda for poverty reduction and the inclusion of people with disabilities and their families. The following outlines *Inclusion International*'s efforts to respond to these issues of social exclusion by drawing from the knowledge of our membership in over 200 countries around the world and by mobilizing that knowledge to impact on governments and donor agencies.

Achieving Human Rights Means Addressing Social, Economic and Political Exclusion

While significant poverty reduction strategies are being developed by governments, multi-lateral agencies and international financial institutions, issues of equity, participation and inclusion are left to human rights and legal judicial mechanisms for attention. The result is a disconnect between human rights systems and the systems that generate and control wealth. Current initiatives to combat poverty through international financial institutions and governments are not effectively, if at all, evaluating the exclusion of people who have a disability from economic and social participation in the construction of policies.

Civil society organizations active in international cooperation and development have become in many instances the delivery agents for these supports supplying a parallel and substandard social infrastructure. This model of social and economic development has proven unsustainable and ineffective because the real barriers to inclusion lie in the structure and implementation of social and economic policy. While services and supports are important elements in the lives of people who have a disability; and disability specific rights raise awareness of the issues affecting people who have a disability, it is mainstream policies and investments in education, poverty reduction, health care, strengthening civil society, child protection and others that have the greatest impact on the inclusion or exclusion of people who have a disability.

An Expanding Role for Disability and Family Organizations

In analyzing the slow progress toward inclusion, it is increasingly evident that while significant knowledge exists about how to make inclusion happen in discrete communities, schools or other settings this knowledge is not being translated into resources which can be used in decision making about policy development or investments by governments and multilateral agencies. What is needed are strategies to translate *what we know about inclusion, how it works in communities and why* into structural, economic and social policies that governments, donor agencies and international institutions can adopt and implement as a part of mainstream sustainable development plans.

This means that traditional strategies of advocacy organizations to act as watch dogs and service delivery agents must be expanded to include other roles such as knowledge brokers and advocates for policy change. This shift is not unique to the disability sector, the increasing global trend toward democratization has opened up the political space for civil society organizations to play a more active policy influencing role.

Some Strategies and Tactics Employed by CSOs

Strategies	Tactics	Skills
Education	Meetings, media, workshops, conferences, commissions	Research, information, analysis, dissemination, communication and articulation
Collaboration	Building relationships, links, cooperate with governments and other CSOs	Communication, organization, mobilization, networking technical capabilities, transparency openness and effectives
Persuasion	Meetings, workshops, coalition, lobbying, media, demonstration	Organizing, communication, motivation, negotiation, commitment and vision
Litigation	Use of courts	Legislation, communication
Confrontation	Demonstration, public gatherings, speeches	Mobilizing, communication, motivation, leadership

Chart 1: Role of Civil Society Organizations in Governance, Dr. Aisha Ghaus-Pasha, December 2004, United Nations

Traditionally we have used strategies such as awareness raising; litigation and protest to place demands on the state. We believed that the establishment of human rights for people with disabilities would lead directly to the achievement of those rights. International cooperation between disability organizations continue to emphasize the need to establish a framework of rights in developing countries and countries that are in the processes of democratization. We know now that rights are not

enough. We need strategies to help governments and donor agencies develop inclusive policy approaches.

Persuasion/Awareness Raising

The first challenge we face is in establishing disability as an issue that donors, international agencies and *International Financial Institutions* (IFIs) recognize within their priorities. A recent study done by II of selected donor agencies showed that few had policies on the inclusion of people with disabilities in their development priorities and none had successfully incorporated disability across development priorities.

One reason for this has been that the current emphasis on the United Nations MDGs has left out any reference or consideration of people with disabilities. For this reason II developed a strategy to demonstrate how each of the MDGs is relevant to people with intellectual disabilities. The II MDGs provide both targets for the achievement of each MDG for people with disabilities along with evidence of the particular vulnerability of people with disabilities – especially people with intellectual disabilities (see chart 2).

To be effective we need evidence that these issues are substantial and will impact on the achievement of the MDGs. For example in the area of education it is not sufficient to point out that less than 2% of children with disabilities receive an education; rather we must show that 40 million of the 120 million children who are out of school have a disability. This means that achieving the MDG on Education requires strategies to develop inclusive education systems. It puts the issue in the mainstream development agenda.

Education/Knowledge Development

If we are successful in establishing the importance of our issues in relation to the larger policy agenda (MDGs) it will likely generate investments in research and knowledge development by governments and donor agencies. As the World Bank for example, begins to consider the relationship between poverty and disability, it has begun to invest in data collection and to encourage governments to determine what portion of national populations are impacted by disability. However the information produced by these processes (census data for example) provides only a static and one dimensional picture of the issues affecting people with disabilities. The knowledge that people who have a disability and their families have is of the relationship between people with disabilities and their families, their communities and the social, economic and political structures with which they interact. It is this knowledge that provides a real understanding of the barriers to participation and inclusion. Civil society organizations are a key source for this knowledge and must be supported to share and contribute this knowledge with governments and donor agencies.

Collaboration/ Policy Engagement

Even where there is evidence that the issues affecting people with disabilities are important in achieving development objectives and where data and information is supplemented by real knowledge about the issues of exclusion, disability and family based organizations need to play the role of translating these issues into policy. We now know that people with disabilities are at increased risk of HIV/AIDS infection; we understand that this is due to their vulnerability in society and the lack of access to public education programming as well as cultural myths about disability that exist in many countries. What policy issues does this raise for governments and for donor agencies? A simple response would be prevention education targeted at this population. But if these prevention programmes are delivered through schools: are young people with disabilities in school, how will deaf people hear public awareness campaigns on the radio etc.?

Being part of defining the policy issues is critical if we are to achieve inclusion but grassroots organizations need the capacity and skills to know what to ask for. Much has been made of the fact that people with disabilities and the organizations that represent them have been left out of the Poverty Reduction Strategy Paper consultations and the fact that disability where mentioned in PRSPs is seen as a social protection issue. Little has been said about the fact that DPOs in many countries do not have the resources or skills to contribute to this process beyond the identification of issues. Family based organizations may identify needs (services and disability aids for example) but few would have the capacity to introduce tax reform measures to support families who have a member with a disability or teacher training and curriculum adaptation strategies for inclusive education. Building this capacity requires investment in civil society organizations and knowledge networking strategies. II's MDGs have proven to be a valuable communication tool that helps to raise awareness about the link between poverty and disability but they are also an important framework for advancing a policy agenda for inclusion.

To be effective beyond awareness raising, civil society organizations like II must become sources of

Inclusion International MDG's	Data Shows	What We Know From People
1. Eradicate Extreme Poverty For People with Disabilities and their Families	*The World Bank estimates that people with disabilities account for as many as one in five of the world's poorest people, suggesting that 260 million (43%) of the estimated 1.3 billion people world wide living on less than $1 per day have a disability.*	Due to lack of inclusive education, basic services and health care, people with disabilities are prevented from integrating into society. It is very difficult to gain employment with a lack of training and facing employer discrimination. Without a job or an education people with disabilities cannot break the cycle of poverty.
2. Achieve Inclusive Education	*Recent UNESCO studies suggest the highest incidence and prevalence of disabilities occur in the poorest areas, where less than 2% of children with disabilities attend school.*	The systematic discrimination and segregation of children with disabilities extends to the classroom where teachers have not been properly trained, and inadequate resources are in place to develop inclusive education for all children.
3. Promote Gender Equality for Women with Disabilities	*UNICEF estimates that only around 1% of girls with disabilities are literate.*	Responsibility of care giving falls disproportionately on mothers or female siblings resulting in even fewer opportunities for female family members to gain employment or complete schooling.
4. Reduce the Mortality of Children with Disability	*Mortality for children with disabilities may be high as 80% in countries where under five mortality as a whole has decreased to below 20%.*	The lives of infants with disabilities are often so undervalued that they are not cared for or fed as families struggle with meager resources.
5. Achieve the Rights of Children and Families	*It is estimated that only 2% of people with disabilities in developing countries have access to rehabilitation and appropriate basic services.*	Families report that time to build social networks and support circles, friendships, get involved in their community are consumed with the need to just *get by* resulting in fewer mechanisms for support and limited social capital
6. Combat HIV/AIDS	*The World Bank performed an international survey which concluded that HIV/AIDS is a significant and almost wholly unrecognized problem among disabled populations worldwide.* *While all individuals with disability are at risk for HIV infection, subgroups within the disabled population – most notably women with disability, disabled members of ethnic and minority communities, disabled adolescents and disabled individuals who live in institutions – are at especially increased risk.*	Extreme poverty and social sanctions against marrying a disabled person mean that they are likely to become involved in a series of unstable relationships. Disabled woman are often a target for rape, which puts them at risk. There are almost no sexual education programs targeted towards people with disabilities. The global literacy rate for people with disabilities is estimated to be only 3%, thus making sexual education and HIV/AIDS information difficult to disseminate, especially for those who are deaf and/or blind.
7. Ensure Environmental Sustainability	*UN statistics state that about 20% of all disabilities are caused by malnutrition and over 10% are caused by infectious diseases.*	Poor nutrition, dangerous working and living conditions, limited access to vaccination programmes, and to health & maternity care, poor hygiene, bad sanitation, inadequate information about the causes of impairments, war and conflict, and natural disasters all cause disability.
8. Develop a Global Partnership for Development	*Recent estimates indicate that there are approximately 450 million people with disabilities living in the developing world. Approximately 30-40% of households care for a member with a disability.*	The exclusion and systemic undervaluing of people with disabilities perpetuates a cycle of poverty and isolation. Unless disabled people are brought into the development mainstream by creating global partnerships for advocacy and development it will be impossible to achieve full human and economic rights.

Chart 2: Inclusion International's MDGs

knowledge. Using the II MDGs as a framework for our agenda II has developed a three part strategy:

- Drawing from the knowledge of our members (local families, and people who themselves have a disability) to more fully understand and articulate the profound costs of exclusion to communities and societies;
- Strengthening the capacity of member organizations to meaningfully participate in policy dialogue and governance processes by engaging them in strategic dialogue about the structures and processes that impact on their well-being;
- Effecting the development of inclusive policies and practices at the national, regional and international level by contributing our collective knowledge about why people are excluded; what works; what doesn't and why.

Strategies to advance inclusion must include the establishment of processes and forums which take advantage of the knowledge that exists in communities by building on and scaling up from existing local, grassroots and civil society development activities, experiences and knowledge. The processes must link the knowledge of communities to policy development, implementation and monitoring by governments and international institutions. Shifting from *disability policy* to *inclusive policy* is a critical step in realizing the human rights of people who have a disability. In order for societies to value and respect the contributions of people who have a disability, political, economic and social policies must be designed to be inclusive. *Inclusion International*, its members and networks can play an important role in strengthening the capacity of institutions to adopt inclusive approaches at the global (World Bank, UNESCO, OECD, The G8 etc.); regional (European Union, Organization of American States, African Union etc.) and national (governments and donor agencies) levels.

A Plan of Action

Increasingly governments and international financial institutions are recognizing that real knowledge about how to address the sources and underlying causes of poverty lies with people and communities at the local level who live in poverty. The World Bank's Voices of the Poor research is based on an understanding that the real experts on poverty are people who live in poverty. Likewise people who have a disability and their families are the experts on disability and the factors affecting their inclusion or exclusion. In order to ensure that people who have a disability are considered in strategies and investments to meet the MDG's, *Inclusion International* has designed a global initiative to *Link local knowledge to global change*, bringing the voices of people who have a disability and their families who are also poor to the tables and processes where decisions are made.

Inclusion International is entering the second year of a three-year initiative to draw global attention to the conditions of poverty and their impact on the lives of people who have a disability and their families. The initiative will support people with disabilities, their families, associations and networks to come together in each of the four participating regions (the Americas, Africa and the Indian Ocean, Europe and the Middle East) to develop strategies to identify the causes of poverty and address those conditions. With the financial support of the *Norwegian Association for Persons with Developmental Disabilities* (NFU), member of *Inclusion International*, *Inclusion International* is working with each of its regional associations to host a regional forum at which the initial research findings will be used as a basis for developing strategies and implications for policy in different sectors.

The initiative will use the process leading up to and following each of the regional conferences to build a base of knowledge about poverty and disability. Over the three years of the project II will develop a baseline global report on poverty and disability using the II MDGs as a framework to be released at II's World Congress in Mexico in 2006.

To date reports from the Americas and Africa have been completed and strategies for advancing agendas of poverty reduction in those regions have begun to take shape.

Drawing from the voices of people who have a disability and their families, *Voices from the Americas* (www.inclusion-international.org) provides an analysis of the implications of each of the Millennium Development Goals for people with disabilities and their families: "Listening to families helps us to understand that poverty does not affect only individuals but poverty is systemic human issue affecting families, communities and nations." (Dr. Roberto Leal, Executive Director Inclusion Inter-Americana). By examining the experiences of people who have a disability in the Americas, the report demonstrates that the way in which a person's disability is experienced is significantly impacted by conditions of poverty (personal and community). The findings of this report reflect the need for a shift in the focus of development assistance from addressing disability as unique programming issue to begin to integrate disability issues into government, donor agency and NGO strategies across sectors at the national, regional and global level. It also points to the need for approaches to poverty that acknowledge poverty as an issue of exclusion.

The *Interim Report on Poverty and Disability in Africa* identifies structural reform issues such as good governance and the need for effective processes for civil society participation in policy development along with sectoral issues such as the increased vulnerability if people with disabilities to HIV/AIDS and the need for inclusive education reform.

Parallel processes for collecting knowledge and analysis from families and individuals are underway in Europe (with a particular focus on Eastern Europe) and in the Middle East North Africa for 2005.

Making a Difference in People's Lives

Ultimately, the effectiveness of *Inclusion International*'s strategies can only be measured by whether we are making a difference in the lives of people who have an intellectual disability and their families. Yet measuring progress in this regard is difficult. As an international organization our job is not to deliver projects that help ten, twenty or a hundred individuals at a time, this is the job of our member organizations. Rather II's job is to support our members in their efforts and to scale up that work internationally so as to create change at a systemic level. Making sure that the voices of people with intellectual disabilities are heard and respected in the negotiation of a new UN Convention on Disability; playing a leadership role in having the people with disabilities included in the Millennium Development Goals; providing our members with a platform from which they can take advantage of opportunities such as the Commission for Africa's work. There is some evidence that governments and international agencies are taking seriously the call to include people who have an intellectual disability in their programming and investments. Some results to date that are directly or indirectly linked to our efforts include:

- In Honduras, the national Federation embarked upon an intense lobbying effort and managed to have the state include persons with disabilities as a sector into its national programme against poverty and extreme poverty;
- In Panama, the First Lady will convene a regional meeting of first ladies on poverty and disability drawing from *Inclusion International*'s report;
- In Nicaragua, the Ministry of Health with our member organization has a pilot programme to distribute folic acid, covering 16,000 women residing in four of the areas most affected by poverty;
- In Africa, a network of family organizations across west and south Africa have agreed to collaborate on poverty and disability research;
- The Commission For Africa included children with disabilities in their recommendations on education in Africa.

Inclusion International has committed itself to addressing the systemic issues of social, economic and political exclusion faced by people who have an intellectual disability and their families. To achieve these objectives we will need to have an impact on development agencies, international financial institutions and governments. Our job is to strengthen the capacity of these institutions to develop inclusive strategies for development. It is no longer enough to say we want to be included, now we must show them how.

***Zusammenfassung**: Trotz internationaler Unterstützung von Initiativen zu Gunsten von behinderten Menschen in Entwicklungsländern hat sich deren wirtschaftlicher, politischer und sozialer Status bislang kaum bis gar nicht verbessert. Um zu verstehen, warum Menschen mit Behinderung noch immer zu den am meisten benachteiligten Bevölkerungsgruppen auf der Welt gehören, müssen wir einen Blick darauf werfen, wie sie von politischen Entscheidungsträgern wahrgenommen werden und wie Entwicklungspolitik mit dem Thema Behinderung umgeht. Wenn ein wirklicher Fortschritt im Hinblick auf die Lebensverhältnisse behinderter Menschen erzielt werden soll, müssen sich sowohl die Wahrnehmung von Menschen mit Behinderungen als auch unsere politischen Ziele ändern. Die Autorin unterstreicht die Notwendigkeit eines Wandels von einer Behindertenpolitik zu einer inklusiven Entwicklungspolitik und stellt fest, dass zivilgesellschaftliche Organisationen erweiterte Strategien benötigen, um zu diesem Wandel beizutragen. Die globale Strategie, die Inclusion International entwickelt hat, um die Einbeziehung von Menschen mit geistigen Beeinträchtigungen und ihren Familien in die Millennium Development Goals der Vereinten Nationen voranzutreiben, zeigt, was dieser Wandel für eine internationale Behindertenorganisation bedeutet, und verdeutlicht, wie aus lokalen Initiativen ein globaler Wandel entstehen kann.*

***Résumé:** En dépit d'investissements internationaux pour développer les initiatives visant les personnes handicapées, les investissements par les gouvernements locaux supportant les personnes handicapées et les implications par les gouvernements vis-à-vis des engagements internationaux et locaux des droits de l'homme, pratiquement peu a été accompli pour améliorer la condition économique, politique ou sociale des personnes qui souffrent d'une infirmité dans les pays en voie de développement. Pour comprendre pourquoi les personnes handicapées continuent à être parmi les plus désavantagées au monde, il faut que nous considérions comment ces handicapés sont perçus par les faiseurs de politique et comment la politique de développement aborde l'infirmité. Si un réel progrès doit être réalisé en améliorant la qualité de vie des personnes handicapées, la perception des handicapés et nos buts politiques doivent tous les deux changer. L'étude souligne la nécessité pour un changement de la politique pour handicapés à une politique globale de développement et propose que les organisations de société civile réclament des stratégies élargies pour contribuer à ce changement. La stratégie globale engendrée par Inclusion International afin de promouvoir l'inclusion des personnes handicapées intellectuellement et de leurs familles dans le Millennium Development Goals des Nations Unies, illustre ce que ce changement signifie pour une organisation internationale d'handicapés et démontre comment nous pouvons relier les voix locales au changement global.*

***Resumen:** La autora subraya la necesidad del cambio de la política de la discapacidad a la política del desarrollo inclusivo, y constata que las organizaciones de la sociedad civil requieren estratégias mas amplias para fortalecer este cambio. Inclusion International desarrolló una estratégia global para integrar Personas con Discapacidad Mental y sus familias en las Millennium Development Goals de las Naciones Unidas. La estratégia enseña el significado que tiene este cambio para una organización internacional en el área de la discapacidad, y muestra además como un cambio global puede surgir de iniciativas locales.*

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