Inclusion International Submission to the International Development Committee

re DFID’s Inquiry into Disability and Development

Introduction

There are approximately 1 billion people with disabilities around the world. It is believed that as many as 80% live in developing countries. When families are taken into consideration, it is estimated that disability affects 25% of the population. Using the average estimates that researches and demographers in the field tend to use, about 2% of the global population – or about 140 million people – live with an intellectual disability. While the relatively recent adoption of the UN Convention on the Rights of Persons with Disabilities has helped to raise awareness about disability and increased the focus many governments have given disability, much work remains to be done to secure the human rights and advance the full inclusion of people with disabilities.

Inclusion International welcomes the opportunity to submit a brief to the International Development Committee’s inquiry into Disability and Development. We applaud the committee and DFID’s efforts to ensure that DFID’s policy and programming are responsive to and reflective of the rights and support needs of persons with disabilities. Our brief will focus specifically on people with intellectual disabilities.

Our brief will comment on:

• Shifting from inclusion in development to inclusive development
• Ensuring inclusive investment of funds
• Connecting progressive policy efforts to progressive programming efforts
• Supporting the representation of people with intellectual disabilities and their families.

Lastly, our report will make some recommendations for action to enhance inclusive development.

Inclusion International’s submission complements that of our UK-based member, MENCAP. MENCAP’s submission focused on principles for inclusive education and inclusive employment practice – two top priorities for people with intellectual disabilities and their families around the world.

Who we Are

Inclusion International is a network of over 200 family-based organizations, working in 115 countries worldwide to promote the social, cultural, economic, and political rights of people with intellectual disabilities. II is an assembly of the voices of persons with intellectual disabilities and their families that promotes shared values of respect, diversity, human rights, solidarity and inclusion to achieve a vision of a world where people with intellectual disabilities and their families can equally participate and be valued in all aspects of community life.

II is one of the largest international non-governmental organizations in the field of disability and is one of the 7 members of the International Disability Alliance who works directly with the United Nations. Through its national members, regional level organizations and global organization, II works with
international agencies including the World Health Organization (WHO), United Nations Educational, Scientific and Cultural Organization (UNESCO), World Bank, United Nations Economic and Social Council (ECOSOC), International Labour Organization (ILO), United Nations International Children’s Fund (UNICEF), and regional bodies to promote inclusive approaches to policy, practice and investment strategies.

II has helped the voices of people with disabilities and their families be heard for over 40 years. The inclusion of people with disabilities into their communities, as valued neighbours and citizens, is a priority for Inclusion International and its membership.

Over the past several years the work of Inclusion International has focused on the implementation of the UN Convention on the Rights of Persons with Disabilities and in particular 4 priority areas identified by member organizations as critical to advancing the inclusion of people with intellectual disabilities and their families (See II Strategic Plan http://inclusion-international.org/who-we-are/strategic-plan/):

• Inclusive Education (Article 24)
• Living and Being Included in the Community (Article 19)
• The Right to Decide (Article 12)
• The Role of Families (Preamble)

This submission particularly reflects the experiences and perspectives of our members in Africa, Central America and Asia where they have had direct experience with the impact of development spending.

**DFID’s Efforts on Disability and Development**

DFID has long recognized the need for action to address disability and to tackle underlying causes of poverty and exclusion. DFID’s policy paper on disability and development explored the adoption of a rights-based approach, the use of a social not medical model, and the use of a twin-track approach to achieving equality for people with disabilities.

Further, a 2005 DFID paper, *Reducing Poverty by Tackling Social Exclusion*,

“People need the opportunity to participate fully in the life of their community if they are to flourish and realise their potential. But certain groups in society are systematically excluded from opportunities that are open to other, because they are discriminated against on the basis of their race, religion, gender, caste, age, disability or other social identity. (...) Social exclusion deprives people of choices and opportunities to escape from poverty and denies them a voice to claim their rights.”

To-date, most national-level development and international cooperation efforts and global development efforts like the Millennium Development Goals (MDGs) have not been inclusive of people with intellectual disabilities. While a great deal has been achieved through the MDGs, increasingly, it has been recognized that the gains made through the MDGs have not equally benefited all people – that the poorest and most marginalized, in particular people with disabilities, have been excluded. As the global dialogue on the post-2015 development agenda continues, this inquiry into disability and development is timely.
This submission aims to identify gaps noted in global development efforts and identify areas for action to support DFID to deliver inclusive development.

Shifting from inclusion in development to inclusive development

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.

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 or by 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. Correspondingly, the work of disability organizations has focused on getting in to existing development processes and not on contributing to more effective development.

The result has been that disability may be included in development efforts but in practice, those efforts not only aren’t designed to be inclusive, they perpetuate a medical model of disability and the development of segregated approaches to disability. The model hasn’t shifted from inclusion in development to inclusive development.

Ensuring Inclusive Investment of Funds

Typically, development funding will flow directly to governments, through civil society organizations – including Disabled Persons Organizations (DPOs) – and multilateral agencies like the World Bank or UN agencies. In each of these funding streams there are unique challenges in terms of how to develop inclusive approach to policy, programming and funding.

Funding to Governments

In most developing countries – where the majority of people with disabilities live – people with disabilities remain marginalized and isolated. The impact is that their issues and priorities are often ignored and excluded from government priorities and mainstream efforts. For example, Poverty Reduction Strategies and other country-led efforts delivered with support from development funds, start from a place of exclusion. Without the inclusion of people with intellectual disabilities and their families, these efforts will never be successful. Tracking investments to ensure that disability is identified
in mainstream efforts – as we see with gender – and developing indicators of inclusion can help remedy this.

Additionally, DPOs in many countries do not have the resources or skills to contribute to large processes like PRSPs and development consultations 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. Strategies to support and strengthen the capacity of civil society groups to engage in public policy dialogue and analysis of economic issues will contribute to better economic strategies.

_Funding to CSOs and DPOs_

Often, development funding is provided to large generic development agencies. These agencies often do not have sufficient disability-specific knowledge to adequately include an effective focus on inclusion in their programming efforts. Where the focus does exist it is often for disability specific initiatives focused on rehabilitation or methods of accommodation. While these initiatives are important to support individuals, there is a lack of corresponding programming and investment in transforming systems to be inclusive. Inclusion of people with intellectual disabilities typically requires more than basic accommodations like a ramp or adaptations to buildings. For many people with sensory or physical disabilities access means ensure providing something to the individual (ramps, assistive devices etc.) which enables them to participate on an equal basis. For a person with an intellectual disability, inclusion and participation requires a more systemic approach which might include curriculum adaptation, changes to the way a teacher organizes a classroom, policy reform in employment, new teaching strategies etc.

People with intellectual disabilities have effectively been left behind by many CSOs and DPOs. In many countries, self-advocacy is a new concept and the voice of people with intellectual disabilities has not been built up. While this voice is growing and the movement of self-advocates is building momentum, its development has been uneven. Around the world, the vast majority of adults with intellectual disabilities live at home with their parents— not necessarily by choice but because there are no other options. Most receive little to no support from their government and rely completely on their families to meet their needs (see [www.inclusion-international.org/inclusion-international-global-report-on-living-and-being-included-in-the-community/](http://www.inclusion-international.org/inclusion-international-global-report-on-living-and-being-included-in-the-community/)). History has demonstrated that family-based organizations have been essential in fostering the development of self-advocacy. Yet, many DPOs continue to deliberately exclude family-based organizations from being at the table. Without a strong family movement and a strong self-advocacy movement, people with intellectual disabilities will be voiceless and powerless.

Civil society organizations need to ensure their efforts related to disability reflect current thinking about disability and reject outdated assumptions and stereotypes. Further, there is significant need for innovation in the types of supports and services that civil society organizations are often relied on to
deliver at a country level. Enhanced engagement with and support to local groups of people with intellectual disabilities and their families is essential in making a difference locally and ensuring efforts are responsive to their needs. Additionally, programmes and efforts must be evaluated to ensure they are advancing progressive best practices and supporting people with disabilities to live and be included in their communities.

**Funding to Multilateral Agencies**

In funding to multilateral agencies, DFID must ensure that their funds are being used for programming and efforts that are reflective of the UN Convention on the Rights of Persons with Disabilities and consistent with current examples of inclusive best practices. It is shameful to witness the use of development funding to contribute to the continuation of outdated models of support – particularly institutions and other segregated approaches. DFID must ensure the programming models they are funding through international financial institutions and other multilaterals are not condoning and supporting models that have been discredited and discontinued. Funding should be used to focus on supporting people to live and be included in their communities and where such institutions exist, funding should be used to support their closure.

Transversely, a challenge also exists where there are good examples of inclusive practices being demonstrated by governments and/or other agencies at the domestic level and development agencies have no vehicles for translating those experiences into systemic approaches to disability and inclusion. Linking good domestic innovations to development strategies is an important way to build on knowledge and good practices.

**Connecting progressive policy efforts to progressive programming efforts**

While many agencies have established clear policies on how disability should be included in all aspects of their programming, most lack the capacity and knowledge to implement this approach in practice. For example, understanding that children with disabilities should be included in programmes that support education is very different from knowing how to develop education investments that support that inclusion or effective practices for supported employment. Further, disability specific policies are often siloed from mainstream policy. For example, many development agencies have disability specific policies related to education, yet their mainstream education policy is silent on disability. As huge investments are made in Education for All efforts, few government strategies to reform education systems have included strategies to ensure the inclusion of children with disabilities from the outset. There is an increasing need to develop a global capacity for shared knowledge and experience of how to include people with disabilities across policy issue areas and in mainstream ways.

While a twin-track approach to development can be beneficial, in certain areas like education, it has been ineffectual and had a negative impact on the inclusion of people with intellectual disabilities. An example can be seen from the twin-track investment by donors through country plans on education and budgetary support and delivered through NGOs. Civil society organizations active in international cooperation and development have become in many instances the delivery agents for education 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.

Mainstream education systems not only need additional investments but also require a re-evaluation of the way educational systems are designed. Children with disabilities are consistently recognized as the most excluded group from education. From an economic perspective, international donor agencies recognize that in order to effectively reach those children, existing education systems must become inclusive. It is too costly to have special/systems for children with disabilities and inclusive schools reach a much broader range of learners (therefore they are more cost effective). For education to truly reach all children, it must be designed to be inclusive from the outset, set up in a way that can unleash the potential of all children while also creating environments that teach peace, diversity, understanding and cooperation by example. Inclusive education places the child in the centre of learning and equips teachers with the skills and resources to teach to all children living within the school’s community.

Inclusive education requires substantive educational reform in most traditional education systems in order to be more effective, efficient and participatory. Investing in smaller classes; teacher training practices that enable teachers to teach to all children; curriculum that is diversity-friendly; non-discriminatory practices for monitoring, testing and evaluating student performances; and, investing in accessible school infrastructure and resources for students with various needs (including Braille, audio materials, etc). It also requires parents to get involved in schools and throughout the learning process, which in turn helps to build stronger community networks among and between parents, teachers, school administrators and in some cases local government.

The impact of inclusive education on the wider development process is at threefold: first it provides all children with engaging, participatory and adequately resourced education – education that is designed by nature to unlock the fullest potential of students. Second it forces students, teachers and school administrators to manage and understand diversity. Third it teaches democratic participation by inviting students to participate in the learning process (ie: avoiding the rote learning method) and by engaging parents through committees and councils in the education of their child thereby in the democratic process of participating in decision-making processes.

Similar disconnects between progressive policy and investment in programming that perpetuates and outdated approach to disability can also be seen in the areas of health care, employment, recreation and many other areas that impact the inclusion of people with intellectual disabilities. Efforts are needed to ensure consistency and coherency between principles, policy and programming.

**Supporting the representation of people with intellectual disabilities and their families.**

As noted throughout this submission, people with intellectual disabilities and their families are marginalized and lack the capacity to engage more actively in policy advocacy and efforts for systemic
change. Investments in family-based organizations and support to developing self-advocacy are critically needed. All of Inclusion International’s recent global reports (Poverty, 2006; Inclusive Education, 2009; Living and Being Included in the Community, 2012) have consistently documented that people with intellectual disabilities and their families feel voiceless and powerless. Without investment in building their capacity to have a voice and to be able to translate their lived experience and immediate needs into policy as agents of change, opportunities for engagement cannot be taken advantage of. Simply opening the door or extending an invitation for consultation is an insufficient mechanism if individuals and families have no capacity to enter the dialogue.

Further, family-based organizations representing people with intellectual disabilities must be recognized as having a legitimate voice and role in the disability community and movement. For people with intellectual disabilities, in particular those with more significant support needs, it is their families who are their bridge to community. They rely on their families to give voice to their issues and to interpret their priorities to external audiences. To exclude families is to exclude many people with intellectual disabilities.

Conclusion

Despite some progress, 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. At the same time, the development agenda itself has failed to address the marginalization, exclusion of the poorest people in the world and has done little to reduce the inequalities faced by these groups in society. The challenge therefore for people with disabilities in the development context is not inclusion in development but rather how to contribute to models for “inclusive development”.

DFID is well poised to provide international leadership on advancing inclusive development and making a difference in the lives of people with intellectual disabilities and their families. Further, DFID can support the inclusion of people with intellectual disabilities and their families by calling for their inclusion in the post-2015 development agenda.

Recommendations:

• Strengthen the capacity of organizations of families and people with intellectual disabilities to:
  o Inform public policy approaches to support inclusion (i.e. education, employment etc)
  o Effectively engage in policy dialogues on economic development and planning (i.e. PRSPs)
  o Enhance participation in broad based democratic processes.
• Invest in strategies and processes that build social capital. This means shifting from “consultation processes” to inclusive and meaningful processes that produce innovation, trust and social capital.
• Commit to ensuring no DFID investments are used to build or make capital investments in institutions nor to promote the institutionalization of people with disabilities.
• Monitor multilateral and bilateral investments in:
o **education** to ensure that they are inclusive of children with intellectual disabilities; support inclusive education teacher training, providing teachers with the resources and knowledge to teach all students; and, contributing to knowledge about both policy and practice for inclusive schooling.

o **programmes** to ensure they are consistent with the UN Convention on the Rights of Persons with Disabilities

- Invest in developing the institutional capacity of countries to adequately monitor programmes that promote inclusion – including education ministries and other ministries supporting the delivery of supports, services and programmes to people with disabilities.
- Call for a post-2015 development agenda that is truly inclusive of people with intellectual disabilities and their families; incorporates inclusion as a foundational philosophy, and, contains explicit indicators of inclusion.