

Introduction: Implementing disability-inclusive development in the Pacific and Asia

Pamela Thomas, Development Studies Network, Resource Management in Asia-Pacific Program, The Australian National University

This issue of the *Development Bulletin* considers progress in the Asia and Pacific Regions in incorporating disability within development-related legislation, strategies, planning and practice. It reviews how, and the extent to which, the UN Convention on the Rights of Persons with Disabilities (CRPD) has been implemented to advance the human rights of those with disability and considers, from a variety of different perspectives, the experience and achievements in disability-inclusive practice. This journal is based largely on the papers and discussion from the second ADDC/ANU international disability conference 'Implementing disability-inclusive development in the Pacific and Asia' held in Darwin, September 15–17, 2010, and the two subsequent roundtables on good practice and research.

Viewpoint

In keeping with the *Development Bulletin*'s usual content we are including a Viewpoint section to highlight contributed papers that deal with important, cutting-edge development issues in the Asia Pacific region. The Viewpoint paper in this issue considers the relationship between urbanisation and development and its trends and impact on Pacific Island communities. Rapid urbanisation has particular resonance for the disability and development debate as throughout the Pacific the causal factors underlying urbanisation include displacement, poverty, inequality, lack of access to services and disempowerment — situations that are likely to worsen in an urban setting. Many people with disability will face additional challenges in rapidly urbanising environments. Paul Jones provides an overview of urbanisation in the Pacific.

Background to disability-inclusive development

An earlier issue of the *Development Bulletin* (No. 73) introduced disability as an important but seriously neglected component of social and economic development. It showed clearly that in 2008 neither the academic community nor most of the organisations working in development assistance had considered the inter-relationship between poverty, disability and development. Although global figures suggest that at least 10 per cent of any population has a disability, people with disability have been largely invisible. Their invisibility ensured their continued exclusion from both records and research, and from their human rights, including access to education and health services and economic opportunity. In many Asian and Pacific countries people with disability remained un- or under-enumerated in the official government census. Globally, there was limited awareness of the vicious circle between disability and abuse and the appalling situation of women with disability. Although there is now a considerable literature on violence against women, there has been very little recognition of the very high levels of violence and sexual abuse against women with disability.

This lack of consideration for the link between disability and poverty is clearly shown by its absence from the Millennium Development Goals — although disability impacts on the achievement of most goals. Disability was also absent from the binding instruments of international human rights law, including the Universal Declaration of Human Rights.

The lack of disability within the development agenda began to change with the adoption of the CRPD. It was ratified by Australia in July 2008. In Australia, 2008 saw the establishment of AusAID's Disability Task Force and the Australian

Disability and Development Consortium (ADDC), both strongly supported by the then Australian Government Parliamentary Secretary for International Development Assistance, the Hon. Mr Bob McMullan.

In an attempt to promote discussion and provide greater understanding of the inter-relationship between disability and development, in September 2008, a conference was organised by the Development Studies Network at the Australian National University and the ADDC, and supported by AusAID. It brought the situation to the attention of academics, consultants, government and non government personnel and community representatives from the Asia and Pacific regions and provided the opportunity for in depth discussion on the ways forward to implement the CRPD. *Development Bulletin* No.73 included selected papers and discussion from that conference. This was soon followed by the publication of Australian Government's disability strategy *Development for All: Towards a disability-inclusive Australian aid program, 2009–2014*, an important milestone in the Australian aid program.

Development Bulletin No.74

To critically review the experience and progress with implementing disability-inclusive development in Pacific and Asian countries and to provide an informal evaluation of activities over the last two years, a second international conference was held in Darwin in September 2010. The conference, 'Implementing disability-inclusive development in the Pacific and Asia: reviewing progress, planning the future', was a partnership between the Australian National University, the Australian Council for International Development, National Disability Services and ADDC. It was largely funded by AusAID. The conference, followed by two one-day workshops, provided the opportunity to share the achievements of the previous two years, to discuss disability-inclusive strategies and their implementation, to debate the plans that had worked well in practice and what had not, and to consider implementation for the future. It reviewed practical actions being undertaken in the Pacific and Asia at community, local, national, regional and international levels and included the experience and viewpoint of people from small community-based disability groups, local government leaders, people with disability, legislators, researchers, volunteers, occupational therapists, government and non government development workers from a total of 30 different Asian and Pacific countries. Overall, it provided the opportunity for wide ranging and in-depth discussion on emerging global political, economic and social change and their likely impact on those with disability. Most importantly, it provided a voice for people with disability and an opportunity to network and participate in in-depth discussion. The following papers include their perspectives and recommendations on progress towards disability-inclusive development.

Reading between the lines, the papers in this issue show the importance of small, national or local community-based or non government organisations — especially those that are faith based — in implementing small but important practical, often innovative, activities and services that

provide people with dignity, access and inclusion. The papers also show the importance of equal partnerships, long-term involvement, networking and understanding the specific needs, perspectives and values of those from different cultures.

While some case studies include first-hand experience of discrimination, exclusion, vulnerability and the vicious circle between poverty and disability, the focus of the journal is on progress and positive action.

Perspectives on progress

There has been considerable progress towards disability-inclusive development in the Pacific and Asian Regions, most particularly in developing disability-inclusive strategies, policies, and plans. There are more and stronger disabled peoples' organisations; greater inter- and intra-regional networking between disabled people's organisations; a greater focus on establishing and achieving effective partnerships between disability organisations; and higher levels of financial support for disability organisations and their activities. There is a growing understanding of the intersection between poverty, disability, exclusion and development among government and non government personnel as well as within academia. In response to the serious dearth of reliable in-depth data on disability there is now a stronger focus on disability-related research but still limited academic interest.

There has been progress in disability-inclusive education in the Philippines, Lao PDR, Cambodia, Vietnam, Indonesia and Timor-Leste. Workshops and training programs on disability-inclusive development have been undertaken within regional DPOs, in government and non government organisations working in development assistance both in Australia and in countries in the region. Training has also taken place in AusAID and is now being included in development project design and activities. There are current moves to mainstream disability across all development activities. A twin track approach incorporates specific disability focused activities while at the same time mainstreaming its inclusion across all development planning and evaluation. Above all, the papers here indicate growing government recognition that those with disability have equal human rights and equal access to inclusion in education, health care, economic opportunity and decision making.

Progress with conventions and strategies

Conventions, strategies, policies and plans provide the organisational structure necessary for coordinated and efficient disability-inclusive development. Progress within the regions has included the development of the ASEAN's second Strategic Framework 2011–2015, the Pacific Regional Strategy on Disability 2010–2015, the Papua New Guinea National Policy on Disability, Timor-Leste's Disability Policy; Indonesia's National Plans of Action for People with Disability and a number of laws and presidential decrees in Indonesia, to name a few achievements.

Australia has provided important support for disability-inclusive development in the Pacific and Asia. In his foreword, the Hon. Mr Bob McMullan points to disability as ‘one of the signal issues on which Australia took a lead internationally ... people now recognise that the work the Australian Government and AusAID in disability has been world’s best practice ... best practice about something that advances the interests of the poorest people in the world.’ The development and publication of the Australian government’s disability strategy *Development for all*, towards a disability-inclusive Australian aid program provides the blueprint for directing AusAID funding and technical assistance to ensure people with disability are empowered and enabled to fulfil their mandate under the CRPD.

The strategy has been important in changing how the aid program works. As Kristin Pratt points out building understanding of disability-inclusive development within AusAID itself has led to a number of changes in AusAID programming. AusAID’s scholarship program now provides for more people with disability; program guidelines are now disability-friendly; a disability-inclusive resource facility has been established and two regional disability specialists have been the appointed — one in Cambodia and the other in Timor-Leste. Disability is being mainstreamed into AusAID development programming. Other AusAID achievements have been *Development for All*, a report card/booklet for *Development for All*, a very large increase in funding for disability-related activities, (\$A30 million over four years), the establishment of a high level external disability reference group, support to the Pacific Islands Forum Secretariat to host the first Pacific Forum Ministers meeting on disability and to assist development a Pacific Regional Strategy on Disability (PRSD).

The Pacific Regional Strategy 2010–2015 provides a framework for coordinating development partners, including government and civil society, in building a disability-inclusive Pacific through strengthening political leadership and an enabling environment. The strategy was presented at the Forum Ministers Meeting on Disability in 2009 where leaders reaffirmed their strong support and agreed to support, protect and promote the rights of people with disability. The PRSD is being implemented by governments in collaboration with civil society, regional stakeholders and development partners. Fred Miller, who was involved in the strategy development said it aims to assist an estimated 800,000 Pacific Island people with disability — a number that is increasing rapidly with high rates of diabetes, increasing urbanisation, traffic and industrial accidents, lack of early identification, intervention and referral services.

The value of conventions and strategies is queried by Graeme Innes. While he considered that the CRPD is very important, unless there is a common understanding of the wording of conventions and strategies, this can lead to confusion and frustration and to valuable resources being wasted and opportunities missed — an opinion reinforced by Eva Kasim in her paper on Indonesia and other ASEAN countries. The challenges to implementing the CRPD in

Graeme’s opinion include ‘governments in all societies do not have the necessary understanding of either the experience or needs of people with disability; despite expertise available in the disability community, social and economic exclusion has limited individuals and organisations; effective compliance within the CRPD requires urgent action to empower people with disability and strengthen capacity of their organisations.

ASEAN’s Strategic Framework 2010–2015 includes recognition of the importance of information and communication technology in providing people with disability access to the media and information in appropriate formats. In Indonesia, providing access to information and technology includes SIBI (Indonesian sign language) on TV, digital books and Braille for those with vision impairment. There are also special websites for those with visual and hearing difficulties. The framework has three priority areas: a disability-inclusive ASEAN community; inclusive social development and advancing information communication technologies and media access for people with disability.

Progress with policies

While there has been progress with signing conventions and developing strategies, the Hon. Dame Carol Kidu reminds us that to get government funding a strategy is not enough, a clear policy is needed.

Discussing her own experience as Papua New Guinea Minister for Community Development she writes of the considerable progress at government level in disability-inclusive development but that the key to this success has been strong bureaucratic and DPO leadership, working in strong partnership with civil society, service providers and development partners, and a strong policy. ‘As a very inexperienced Minister I soon learned that no policy meant no money’, she says. As she points out, it is all very well having strategies and policies but much more is needed to make a difference to people with disability and to their families and communities.

Developing a National Disability Policy that is acceptable to communities, to people with disability, NGOs, government departments, the Council of Ministers, DPOs, the UN and donors can be a very long-term, fraught process as the Timor-Leste example shows. After many years of conflict Timor-Leste has a high proportion of people with physical and psychosocial disability and there is considerable government and DPO support for a national policy. But a situation where it had to be developed in four languages, where one of them was not well understood, lack of ministry capacity to support those developing the policy, the lengthy process of review, communication problems and a political crisis all hampered the completion of the policy. Tarcisio Ximenes explains that there is considerable government support for disability inclusion but difficulty in getting universal agreement about content.

As several contributors have shown, policies are not always easy to put into practice. Grimes and Stevens et al, in discussing inclusive education in Southeast Asia, show how in Cambodia, Lao PDR and Vietnam a common problem

was translating national policy into practice — a situation that reflects the international experience. They found that:

in order to achieve some degree of success it is necessary to pay attention to the development of a school culture which will enable and support inclusive practices ... in projects facilitated by development agencies and NGOs, policy statements are often constructed on a set of assumptions that fail to take local cultural factors into account.

Progress for individuals

Although there has been significant progress in Pacific Island countries, people with disability and their families and communities, continue to face prejudice, discrimination and rejection. Children are still consistently excluded from attending school — less than 10 per cent of children with disability have any form of education. The case studies point to a number of very basic changes to the physical and social environments that would greatly assist the inclusion of people with disability. Mobility remains a huge problem in both urban and rural areas — ramps in buildings, including hospitals and schools, sloped curbs on pavements would make accessibility easier. Social access to sports, clubs, night clubs, theatres, cinemas would help the social inclusion of those with disability. In PNG, Richard Mandui's experience is that most bars, night clubs and cinemas do not allow access to people in wheelchairs, citing this exclusion is 'company policy'.

Progress among marginalised groups

Fred Miller draws attention to the situation where:

although some people with disability are becoming empowered, diversity among people with disability needs to be acknowledged and attention paid to marginalised groups — those with psychosocial disability, intellectual disability, multiple disabilities, women and youth and those living in remote and rural areas. Despite helpful laws, policies and systems of practice in some countries, women with disability are less educated, experience higher rates of unemployment, are more likely to be abused, are poorer, more isolated and experience worse health outcomes.

Violence against women with disability is an issue of considerable concern and given the generally low status of women and cultural values of silence in many Asian and Pacific countries it is both difficult to identify and even more difficult to address. It is now becoming recognised within women's movements and academic gender studies that there is a triple intersection between poverty, violence, and women with disability. Women with an intellectual disability and those who are profoundly deaf are at very high risk of sexual abuse. The document 'Violence against women with disabilities' produced by the International Network of Women with Disabilities (October 2010) provides valuable recommendations and guidelines on these issues.

Progress with research

A major difficulty in implementing effective disability-inclusive development has been the lack of reliable data on the prevalence of disability, the different types of disability, the lived experience of disability and the perceptions and knowledge of their rights among those with disability. This is particularly true of ethnic minorities and marginalised groups. Within Australia, there is extremely limited reference material on Aboriginal people with disability and if research is done, it is done from a medical perspective. Damian Griffis reflects on the difficulty of undertaking disability-related research among Aboriginal communities when 'many Aboriginal people with disability do not recognise they have a disability and many acquire disabilities due to preventable health conditions'. In traditional Aboriginal language there is no comparable word for disability — a situation that is likely to pertain among people of other ethnic minorities.

A desk-based review of Asia and Pacific literature on disability and development over the last 10 years found 45 studies that focused on both disability and development — most were from countries with very large populations — India, Vietnam, Cambodia, Thailand and Bangladesh. As Gwynnyth Llewellyn and colleagues suggest, given that Asia has 60 per cent of the world's population this small number of publicly available research suggests considerable difficulties for any organisation wanting to base implementation on disability-inclusive data. Disability remains outside the focus of academic development research, in part because it is still not widely recognised as a development problem — with the consequence of no funding for it; partly because most of what data there is piecemeal, undertaken with little knowledge of the difficulties of obtaining data from individuals with disability. Such data is usually part of a project evaluation and therefore not available for publication. An additional difficulty is that many academic journals are not interested in publishing disability-related papers. Hopefully, with greater understanding of the CRPD this will change. Certainly, ADDC, ACFID and members of academic institutions are doing their best to improve the situation.

Two sets of research obligations are incorporated within the CRPD. They are contained in Article 4 — general obligations and Article 31 — statistics and data collection. Article 31 calls on states to collect appropriate information, including statistical and research data to enable them to formulate and implement policies to give effect to the Convention. Article 4 promotes research and development. Central to the CRPD is that people with disability should be actively involved in processes around issues relating to them, including research. Rosemary Kayess provides information on research compliance and ethical principles outlined in the CRPD.

Participatory research has the potential to improve policy and practice but as Rosemary points out it presents considerable challenges. It takes longer, requires complex qualitative approaches in addition to quantitative methods and requires a delicate balance between stakeholders. But the advantages include partnerships, formal and informal opportunities for people with disability to be included and to

participate in contributing to data, governance and research processes.

Inclusion however can be difficult as Elena Jenkin and Erin Wilson outline in a report on their research experience. An important factor is that there is no agreed definition of inclusion or how it might differ from participation. Notions of inclusion often draw on understandings of exclusion and the need to address barriers to inclusion. The task of inclusion in research, planning, implementation and evaluation in the Pacific and Asia is immense — high mortality of children with disability, invisibility, poverty, very low participation in education, isolation, and the generally low status of people with disability, in particular women, make inclusion and participation extremely difficult.

Using community-based rehabilitation (CBR) as an example Maya Thomas shows that while there is a wealth of anecdotal information on various aspects of the effectiveness of CBR and a number of evaluation reports there is little systematic research giving rise to the general opinion that ‘CBR is data rich and evidence poor’. As CBR becomes an accepted strategy world-wide, a rigorous assessment of its effectiveness and impact is needed. Effective research will require the participation in the research process of people with disability. This requires a body of people with disability who have been trained in participatory research methods. Again, this is a difficult task given the low participation in education of many people with disability. On the positive side, this participatory research processes have started.

Among the key priorities for building research capacity in Asia and the Pacific as outlined in the conference report on the Research Roundtable are: building and maintaining partnerships, information sharing, making disability core business in all aspects of development, and continuing to assert ‘nothing about us without us’ as the principle underpinning the research process.

Partnerships and participation

There is general agreement that good partnerships are a key element in promoting and implementing disability inclusion. Since 2008 there has been considerable progress in building more and stronger partnerships within and between organisations involved in disability-related development. In part this flows on from the work involved in strengthening the capacity of DPOs and including a greater number of people with disability in national, regional and international disability activities. In the final analysis, access to funding is critical. As Diana Samarasan of the Disability Rights Fund points out, adequate and well timed funding can promote and support effective partnerships.

Maryanne Diamond, outlining her 20 years experience reminds us that building effective partnerships is a long-term process than requires trust, mutual respect, good communication, as well as a careful selection of appropriate partners. In addition, partnerships rely on a good understanding of different cultural values and ‘the ability to build on the strengths of the countries where we work’. Partnerships between Asian and Pacific countries and the

Australian Government volunteer programs (AYAD and VIDA) provide examples of partnerships in implementing disability-inclusive development that lead to long-term association and support. Approximately 30 per cent of all AYAD and VIDA assignments have an Australian partner organisation.

Progress with social inclusion

As Richard Mandui explained, social exclusion is a very common situation for people with disability and one that is difficult to address. Huy Nguyen of Engineers without Borders provides an innovative approach to overcoming social exclusion. Using his experience in Australian universities, he outlines how he has used a social model of disability (SMD) to increase social inclusion for people with disability in Australia. He feels this model can be applied to developing countries. Essentially, the SMD takes the causes of ‘disability’ away from the individual and places them with the environment and the people within it. It makes people aware of the social and physical barriers that separate people and overcomes the community perception that a person with disability is someone who is not physically normal or uses a wheelchair. The key to this is finding commonalities — language, experiences, friends, ethnicity, religion, etc and building on these. He provides detailed case studies on his SMD activities.

Sport is another important way to promote social inclusion. From the experience of Fred Fatiaki, it is important for people with disability to have fun — to be able to participate in enjoyable social activities. Sport provides the opportunity for participating in a team, to be active and for enjoyment. Sport is particular important for young people with disability and as Richard explains in PNG, people with disability have fairly recently been included in their national games. The success of sportsmen and women has had a dramatic impact on people’s perception of disability and on its social acceptability.

Culture and ethnicity

Culture is shown to be a very important but little recognised factor in disability-related research, planning and implementation. Lack of recognition of different cultural values, perspectives, viewpoints and needs, can lead to a failure in data collection, planning and policy development. Using an Australian example, Sibylle Kaczorek explains that in over 15 years experience her organisation (NEDA) found that culture has considerable relevance to international development work in general and to disability-inclusive development in particular. Her paper highlights the impact of culture and ethnicity on the ability of people with disability to access services. And as Damian discusses Australian Aboriginal people with disability:

when a whole community struggles, having a disability is not seen as anything particularly different because everyone in the community struggles. An important problem that is not recognised is the psychosocial impact of colonisation and displacement. This is not understood

and the Mental Health Service has difficulty in knowing how to address it.

Psychosocial disability

Information on psychosocial disability and its relationship to development remains sparse and case studies even more so. It is the aspect of disability-inclusive development that is to a large extent overlooked or relegated to the too hard basket. The aid program provides funding for avoidable blindness, support for hearing impaired, those with mobility difficulties and is working towards great access to education, health services and economic opportunity. Those with psychosocial disability are virtually invisible in aid programs yet they are a particularly vulnerable group which according to the World Health Organisation (WHO), 'deserving targeted attention in development efforts'. In their 2010 report 'Mental Health and Development: targeting people with mental health conditions as a vulnerable group' WHO 'places a duty on countries to ensure that the rights of people with mental health conditions are protected and that development efforts are inclusive of, and accessible to, people with disabilities.'

David Webb maintains that while there is much to be commended in this report, 'a closer reading reveals an example of WHO's participation in the medical colonisation of psychosocial disability.' As in other aspect of disability, the medical approach rather than a human rights approach dominates. This is an area that requires much further discussion and inclusion within the disability and development debate.

Special issues in implementing disability-inclusive development

In addition to the discussion on empowerment, access, inclusion and human rights there are additional situations that require specific consideration for people with disability. These include the protocols that need to be put in place to protect people with disability in the event of emergencies, disasters, conflict and other unexpected events associated with climatic and political change and rapid urbanisation. In natural and man-made disaster people with disability are usually forgotten. In the rush to escape the disabled are frequently left behind. David Lewis raises the issue of climate change and the likely impact on people with disability. He suggests that funds assigned to climate change, severe weather and other related emergencies, need to include plans and considerations for those with disability. Their needs must also

be included in the reconstruction phase where universal accessibility standards should be applied. David calls for disability needs to be mainstreamed and to be included in specific disability programming. Maryanne also calls for greater understanding of the needs of people with disability in times of disaster and for building partnerships to plan for coordinated disaster responses and follow up.

Conclusions and ways forward

This issue of the *Development Bulletin* indicates a broad consensus on the following:

- effective disability inclusion needs to involve a diversity of stakeholders, partnerships and a wide range of participants;
- a human rights approach is fundamental; and
- government engagement and action is essential

The case studies and the report of the Roundtable on implementing disability-inclusive development demonstrate that common challenges exist in all developing countries in relation to disability and disadvantage. The wide range of cultures and contexts require different frameworks for action. However, there are common features that constitute 'good practice'. These are:

1. Plans and activities are based on reliable in depth data including the lived experience of people with disability, their families and carers.
2. Active inclusion and involvement of people with disability at every stage of planning, implementation and evaluation.
3. Practical actions based on human rights.
4. Equality in partnerships, building on existing strengths.
5. Assistance from donors and development partners based on consultation and agreed needs.
6. Strong leadership and good governance.
7. Long-term involvement in building partners, capacity building and implementation.
8. Inclusive community involvement.
9. Accountability and sustainability.

Good progress has been made in a relatively short space of time. This progress now needs to be built on and lessons learned from experience to date, and the enthusiasm and hard work continued into the future. Finally, we need to keep in mind and apply the definition of TEAM:

Together Everyone Achieves More.