Development
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Network

Implementing Disability-inclusive Development in the Pacific and Asia

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The Network provides information and discussion on social, economic and environmental development issues. It is in regular contact with development-related academic courses and organisations, government and non-government development organisations and community-based development groups. The Network publishes the *Development Bulletin*, a journal that focuses on cutting edge development issues, development theory and practice. It runs occasional seminars on development policy and annual conferences on international development.

The Network is located within the Resource Management in Asia–Pacific Program at the Research School of Pacific and Asian Studies at the Australian National University.

The Development Bulletin

The Bulletin is the journal of the Development Studies Network. It is an occasional publication that is available in hard copy and online for free download. The Development Bulletin includes commissioned and submitted papers. Each issue focuses on a specific development topic and provides papers from multi-disciplinary perspectives. The Bulletin, while academic in focus, is accessible to a wide range of readers. It includes papers and case studies from both academics and non-academics and those working in a range of government, community and non-government development activities. Papers are short and concise.

Each issue also includes background information, suggested literature, useful organizations on the specific topic.

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Implementing disability-inclusive development in the Pacific and Asia: Aspects of human resource development

Papers and case studies include some of those presented at the international conference 'Implementing disability-inclusive development in the Pacific and Asia', Darwin, September 15-17, 2010. Some case studies are taken from conference discussion transcripts.

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Australian **Disability+Development** Consortium

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Acronyms

ABI	Avoidable Blindness Initiative
ABV	Australian Business Volunteers (formerly AESOP)
ACFID	Australian Council for International Development
ADDC	Australian Disability and Development Consortium
ANU	Australian National University
APCD	Asia-Pacific Development Centre on Disability
ASEAN	Association of Southeast Asian Nations
AusAID	Australian Agency for International Development
AYAD	Australian Youth Ambassadors for Development Programme
BMF	Biwako Millenium Framework
CEAD	Centre for Education Access and Development
CRPD	United Nations Convention on the Rights of Persons with Disabilities
DLSP	De La Salle Philippines
DPI	Disabled People's International
DPOs	Disabled People's Organisations
DPI/APs	Disabled People's International Asia Pacific
DRF	Disability Rights Fund
DSOs	Disability Service Organisations
ESCAP	Economic and Social Commission for Asia and the Pacific
GPDD	Global Partnership of Disability and Development
IAPB	International Agency for the Prevention of Blindness
IFB	International Federation of the Blind
ILO	International Labour Organization
INWWD	International Network of Women with Disabilities
Lao PDR	Lao People's Democratic Republic
MDGs	Millennium Development Goals
MSS	Ministry of Social Solidarity – Timor-Leste
NDA	National Disability Agreement
NEDA	National Ethnic Disability Alliance
NGO	Non-government Organisation
NZAID	New Zealand Agency for International Development
PDF	Pacific Disability Forum
PEDF	Pacific Education Development Framework
PICs	Pacific Island Countries
PIF	Pacific Islands Forum
PIFS	Pacific Islands Forum Secretariat
PNG	Papua New Guinea
PRSD	Pacific Regional Strategy on Disability
PWD	People with Disability
RDO	Regional Development Officer
SDAC	Survey of Disability, Ageing and Carers
SDEAS	School of Deaf Education and Applied Studies
SMD	Social Model of Disability
UN	United Nations
UNDPI	United Nations Department of Public Information
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UNHCR	United Nations High Commissioner for Refugees
VIDA	Volunteers for International Development from Australia
WB	World Bank
WBU	World Blind Union
WCWB	World Council for the Welfare of the Blind
WHO	World Health Organization
WHO-MHSA	WHO Department of Mental Health and Substance Abuse
WNUSP	World Network of Users and Survivors of Psychiatry

Foreword

Implementing disability-inclusive development in the Pacific and Asia: Reviewing progress, planning the future

The Hon. Bob McMullan, former Member of Parliament and Parliamentary Secretary for International Development

The work we have been able to do together for people with disability in developing countries has been the proudest part of my community life. One of my grave concerns when I became the Shadow Minister for International Development even before becoming the Parliamentary Secretary is that the rights and interests of people with disability in developing countries were not sufficiently taken into account. I don’t pretend I knew very much about the issue and I set out to find out more. It was people, such as those doing the research, the people campaigning and advocating on behalf of people with disability and those who actively provide support every day to improve the lives of people with disability who inspired me, informed me and helped me develop a policy and I want to thank you all for that.

We all know that the Convention on the Rights of People with Disabilities (CRPD), gives us a framework on which we can build so that the interests and rights of people with disability in all countries are protected and their interests advanced. That is a strong basis on which to build. We have to appreciate that it is a basis, a framework, that is necessary, but not enough. To be consistent with the Convention, we must assist other countries implement it because we accepted an obligation under the Convention to help developing countries to meet their Convention obligations. Nobody seemed to be looking at that clause. People were doing things domestically, and that is very welcome, but the developed countries were ignoring the obligations they had taken on under the Convention to assist people with disability.

What I found very impressive and welcome was that the issue of disability became one of the signal issues on which Australia took a lead internationally. Internationally, people now recognise that the work the Australian Government, AusAID and I, with your help, have been able to do has been recognised as world’s best practice — world’s best practice about something that advances the interests of the poorest people in the world. That should make us all feel proud. People with disability in developing countries tend to be the poorest of the poor and until we do something about their rights and making sure that national development strategies reflect their rights and interests, they will continue to be the poorest of the poor. Not because people in developing countries are heartless and don’t care about them or families in developing countries don’t love their children and don’t want to get them the best future, but because the resources are not there.

If we can make it possible for countries to provide education to children with disability, to provide employment opportunities, to just create the basic level of access to community facilities that everyone should be able the take for granted, then we will have done something about transforming the lives of some of the poorest people in the world and if we can get their rights recognised, if we can say, ‘Not only is this something that needs to be done, but we need the people with disability taking the lead’, then we will have not only have transformed their lives, but we will have transformed their rights.

So, my concluding message is not one of complacency but one of optimism. We have taken the lead. We need to build on it and I am absolutely sure that if you, as individuals and collectively, maintain your advocacy, maintain your enthusiasm and your commitment no Australian Government in the future will ever be able to turn their eyes away from the interests and rights of people with disability in developing countries. I want to conclude with a simple message: I thank you for the work you did long before I came along and got involved. I thank you for the help you gave me in developing *Development for All* and in communicating it to the nation and to the world. I urge you to continue to be engaged in this issue, as I intend to be, so that we can all say ‘we did everything we could in a cause that was worth fighting for’.

Addressing disability and equality in the Northern Territory: Some achievements and lessons learned

The Hon. Kon Vatskalis, MLA,
Minister for Health, Children and Families, Northern Territory, Australia

It is an exciting time for the Minister responsible for disability in the Northern Territory of Australia. There is a national focus on disability reform through the National Disability Agreement (NDA) and agreement of a National Disability Strategy. It has been a long time since the issues facing people with disability have had such a focus. Families now are rightly demanding a greater say in determining their future and in expecting a choice and range of quality service options.

The Northern Territory Government provides disability services over 1.4 million square kilometres. We have around 12,000 people with severe or profound disabilities. The difference in the age structure of those with disability in the population suggests that the number of people with disability is projected to grow at a faster rate than the general population. It is expected that a significant growth in numbers of people with disability will occur in the 65 plus age group and the 45–64 year age group.

There is a significant difference in the burden of illness and disability between the Indigenous and non-Indigenous populations. Forty per cent of people with disability and 40 per cent with profound disability are Indigenous, 39 per cent of whom live in remote areas.

Challenges and achievements in disability inclusion

The Northern Territory Government, as with other jurisdictions, faces a number of unique Northern Territory challenges in addressing the high levels of people with disability. The Northern Territory covers a very large area that is very sparsely populated. There are very few towns and the distance between them is enormous. There are few roads and many Indigenous communities are very difficult to access. This situation requires significant changes in the delivery system for disability services.

In 2006, the Northern Territory Government funded a review of disability services in the Northern Territory. This involved consulting with staff, disability providers and disability service users. In 2007, the Government accepted their recommendations and is implementing them. I am pleased to say the key elements have been achieved. These include:

1. The implementation of a program model with standardised intake and assessment, individual planning and monetary processes for all clients linked to a practice manual. This is occurring in Alice Springs and Darwin and includes information and intake and response to calls from a central contact number.
2. The expansion of day-option services, including a new day-option program for clients in 2009 and the expansion of day-option in Darwin. Now people have a choice of options.
3. Increased accommodation places by 35. To achieve this, in 2009–10 the Northern Territory Government invested an additional $80 million in the disability service system.
4. Other achievements outlined within the National Framework include development of the whole of government approach to disability implementation. The whole of government framework is now focused on developing mainstream services for people with disability. This links with both our own disability service review and the National Disability Strategy that was unveiled in draft form 29 July, 2010. Implementing the National Disability Strategy.

The strategy looks beyond the disability support system delivered under the NDA and is a whole of community response. The aim is to achieve progress in mainstream areas, such as education, health and transport, to name just a few. The Northern Territory Government has signed up to the National Disability Strategy which sets out a 10-year national plan for improving the lives of Australians with disability, their families and carers. It is a whole of government policy framework that engages all levels of government in action to meet the commitments. It provides a method by which they can demonstrate commitment to the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Disability action plans are a way for organisations to plan for elimination of discrimination. This includes talks with stakeholders and setting out proper and appropriate strategies which involves people with disability as valued members of our community. By supporting government agencies in the first instance to develop a response to providing goods and services to people with disability we aim to support the people of the Northern Territory. Work is currently under way to incorporate this approach within the public sector.

The Northern Territory Government has engaged the National Disability Services in the Northern Territory to develop and implement a quality framework. A trial of a range of tools is under way across NGOs within the aged and disability program with the aim of identifying preferred tools for implementation across all service providers. Participants in this process to date have been exceptionally positive about the development of a quality framework.

While the Northern Territory is developing its own framework it is also working with other jurisdictions towards a National Quality Framework. It will share a vision of the national standard of certificates to measure the outcomes and modernise language and concepts to better reflect contemporary organisational structure. Jurisdictions will undertake what the total disability standards align with and go back to the national standards for disability services where gaps are identified.

Despite this work, which will strengthen the quality of service development in the Northern Territory, a number of challenges still remain, including developing a robust and sustainable service system in remote settings.

Providing services for remote and Indigenous communities

Indigenous Territorians have the greatest rate of disability. We rely on community care systems for the needs and arrangements that are often difficult to sustain. These need to be tackled to allow for a broader range of sustainable services in the remote areas. Agreements between the Northern Territory, South Australia and Western Australia is one mechanism that has been used to address this in the central region of our country.

Alice Springs, a town in the centre of Australia, is an important cultural centre and traditional meeting place for many different groups of Indigenous people. We have people moving from South Australia to Alice Springs not only for cultural reasons and shopping, but also if they have to address issues of health and disability. The same thing happens with people with health problems or disability problems from Western Australia. To give an example, we have a significant number of people from other states who come to Alice Springs to have dialysis. That puts enormous pressure on our system and accommodation and we are developing special arrangements with the Western Australian and South Australian Governments.

Services for children

If we accept that services can reduce the impact of a person's disability we have responsibility to increase capacity in this area. In this respect I am pleased to announce a pilot program targeting children with newly diagnosed disability. This is working to develop and model a service which will provide intense support to mothers and their children with disability for several periods throughout the year. It will be a service provided at home and within the community. This program has been well received currently and it will allow us to expand implementation and look at the outcome for these children and their families.

It is important to ensure that funding is accessible for building services that can't be provided elsewhere. People with similar needs should be receiving a similar level of services no matter where they live. However, this is a fundamental challenge. With no service caps, it is not a priority for lobby groups so we continue to run the risk that services are not directed to those who are most vulnerable. This includes children and Indigenous Territorians. A number of options are used to manage this including philanthropic and volunteer involvement in provision in a limited market. Some of the strategies may be very difficult to achieve. I am pleased to report that recently implementation of a resource allocation tool has been directed to those remote regions. The plan will also be ongoing.

There is much to do for the future and there is an opportunity for innovative thinking to address this difficult problem. As you can see there have been many achievements, but we still have a great deal to do, both locally and nationally, to bring people together to work in partnership but I am confident that in future people with disability will achieve equity and access in their daily lives and take their rightful place as valid members of our society.

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.

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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 in 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.

Implementing disability-inclusive development in the Pacific and Asia: Reviewing progress, planning the future

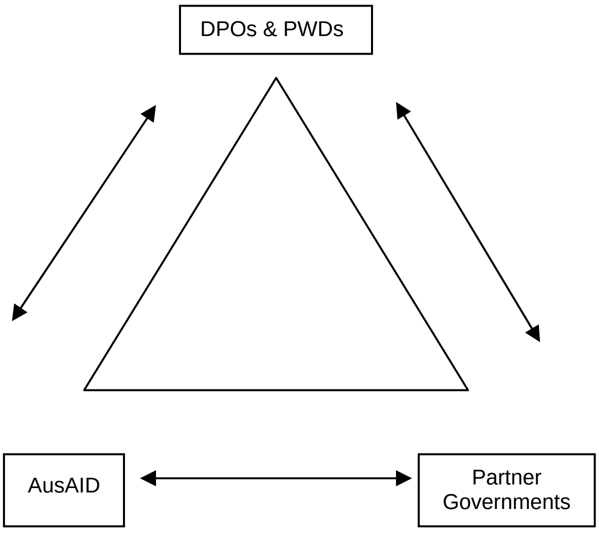
Kristen Pratt, Disability-Inclusive Development Team, AusAID

I would like to cover four points — how AusAID is contributing to meeting the Australian Government's obligations under Article 32 of the UN Convention on Rights of Persons with Disabilities (CRPD); some early achievements with our work; some of the issues and lessons we are finding and how we hope to go forward over the next year or so.

Article 32 of the Convention – *Development for All*

The goal of the *Development for All, towards a disability inclusive Australian aid program strategy* is to change how AusAID engages in and 'does' development so that people with disability are included in, and actively contributing to, AusAID's processes, for example prioritising what happens in the aid program when designing development assistance programs and, importantly, monitoring their impact. We want to ensure that people with disability have better access to and ultimately share equally in the benefits of Australia's development assistance. So this strategy is actually about organisational change for AusAID. It is not a stand-alone disability program like our education or our infrastructure program. It is about dramatically and comprehensively changing the way that AusAID operates.

I would like to highlight three essential aspects of the drivers that we are focusing on. Imagine a triangle — it doesn't have to sit in any direction. There are three points: one point is AusAID, Australia's development assistance agency; another point is DPOs and people with disability; and the third point is the governments with whom AusAID works closely.



These three points of the triangle are what the *Development for All* Strategy is focused on. On each side of that triangle there are arrows going in both directions. So for instance, in relation to people with disability, we are working very hard to make sure they are influencing and advising AusAID on how we do our work — our processes, priorities, and designs and monitoring.

On the AusAID side of the triangle, we are trying to direct resources, in terms of funding and technical assistance to ensure that people with disability are empowered and enabled to fulfil their mandate under the Convention and engage and drive work around the Convention.

On the DPO to government side of the triangle, it is similar. We are hoping that our resources will assist in carrying out work driving national inclusive development with national governments. The arrow going the other way is what all governments should be doing. It is about good governance — governments meeting the needs and priorities of *all* citizens.

On the government side to AusAID, there are another couple of arrows. There is the arrow of AusAID support to partner governments, to assist them and build on their efforts towards inclusive national development. What we really hope for is that the arrow will go the other way — and this will be one of the most powerful parts of that triangle. The way that AusAID works is that we engage with the governments around their national development. They set their priorities and we talk together to agree on how Australia can best assist them. If governments are putting disability-inclusive development on the agenda, our work is really done. It is ownership and we must support it. We hope the *Development for All* strategy will work in that way — enabling, empowering and supporting.

The role of the strategy in relation to AusAID is about changing how we work — the *mainstreaming* or the *integration* aspect. The aspects around supporting, empowering DPOs and partner governments are what we call the *disability-specific* aspects. Obviously there is a lot more that underpins the bodies of work, a lot more work we are doing for the *Development for All* strategy, but from where I sit, that is the main game — supporting partner governments and DPOs to effectively drive this important work themselves.

Achievements

I would like to highlight some of the early achievements. We have developed a booklet which will be our first ever report card on *Development for All*. It is a hard look at progress to date, where we are at in terms of where we had hoped to be. I expect that it will be completed by the end of the year, hopefully launched soon. I expect that it will become our key communication and accountability tool. From the beginning we have tried, with Bob McMullan, to make our work very transparent, very inclusive, very open and this is an important part of that process for us.

2009 was a big year for the AusAID Disability Inclusive Development team, in terms of getting the foundations in place. Planning and figuring out who our partners are and perhaps, more importantly, securing the resources to do this work. Many of you might be aware in the May 2010 budget the Government allocated $30 million over four years to support the disability-specific work of *Development for All.* Having resources and a new budget measure means we have the resources to effectively deliver on the objectives set out in the strategy. Budget funding also gives the work a certain profile and the requirements to report on outcomes and progress to government.

One of the early achievements last year, that was very important from my point of view, was the establishment of an external high-level strategic disability reference group. This is a group of experts to guide the implementation of *Development for All* and also to ensure the ongoing transparency and accountability for how we work. Disability-inclusive development is new for AusAID. There are only a few of us who have been involved in disability for many years, so the scale of organisational change required in AusAID is significant. We need assistance to do that and are fortunate to have a very high-profile, experienced, impressive group supporting us with our work. They have been crucial to the success and the profile over the last 18 months. If you are interested in the work of that group and how it is helping us, the communications from those meetings, which is at the moment twice a year, can be found on the AusAID website along with details about the members and also the terms of reference for the group.

One of the other important achievements was Australian leadership on disability-inclusive development, in particular that of Bob McMullan. We are deeply feeling the loss of his exceptional leadership and are aware that many are concerned about how Mr McMullan's role as a domestic champion amongst his colleagues in Parliament, but also a global champion for disability-inclusive development, will be continued. Over the past three years he successfully raised the profile of disability with our development partners internationally through his leadership and participation in events like the Conference of State Parties. He was seminal in supporting Australia's work in driving a resolution around realising the MDGs for people with disability that was adopted last November. At the regional level, we also had his support to work with the Pacific Island Forum Secretariat and their efforts to host the first ever Pacific Ministers Meeting. Having specific leaders at the Forum Leaders Meeting recognise disability and place it on the agenda was a major achievement that is very important for our work regionally.

As well as leadership, some of our foundation work over the past year or so was around partnerships with key organisations that will be supporting this work. Obviously, DPOs were one of our top priorities and we are pleased to be working closely with the Pacific Disability Forum who exist to strengthen and support DPOs' work and promote ownership and action in this area in the Pacific. Early on we started on that corner of the triangle I mentioned around supporting governments and Mr McMullan signed letters with his counterparts in Cambodia and East Timor to assist their efforts in inclusive national development. We are also in discussions with governments of Samoa and Papua New Guinea.

We established early collaborations with UNICEF in terms of children with disability and the WHO on a range of fronts, not least, the upcoming World Report on Disability which we are very much looking forward to being released. That is a very quick snapshot of some of the achievements we have had over the last 18 months.

Issues and lessons

In terms of disability-inclusive development we have learned a number of lessons. I think a really important one for us, but a really tough one, is staying true to the strategy. That means staying targeted and sequenced and not trying to do everything at once. That was a strong message coming through in our consultations. It is very tempting and very easy to lose our focus and say 'yes' to every request ending up doing a lot not very well. For those of you familiar with the strategy, within AusAID we are trying to focus on integrating disability in the education and infrastructure sectors. They are growing and important sectors, not only for AusAID, but obviously for people with disability, in terms of empowerment and access.

Another key issue for us is that there is absolutely no doubt in our mind that a twin-track approach was the right way to go. We can talk all we like about AusAID changing the way it does its work, but unless we give people with disability appropriate support and resources, and unless we have those other drivers — governments and DPOs pushing that agenda — not a lot will change. The twin-track approach was the right way to go and having resources to support that has been crucial.

An interesting point for me has been the power of building understanding of disability-inclusive development in AusAID. What we are finding is that once people in AusAID gain an understanding of the issue and why it is critical to effective development they just get on and do it. In fact, there is much more that is going on in AusAID than I have been able to mention and many of our teams, particularly our Philippines team, are doing tremendous work. They already have completed a situational analysis on disability that is influencing all of AusAID's programs in the Philippines.

We have seen AusAID's scholarships program change their guidelines and we are now seeing more scholars with disability coming through. Just that simple step of helping AusAID staff understand the nature of the issue and how it is core to AusAID's work and core to the achievements of the MDGs has been critical. Last, but absolutely not least, and we will once again be looking for support from you all on this, is the importance of leadership. You can see the power that high-level leadership has had on bringing profile to this work, not only domestically, but globally.

The other important function that Mr McMullan has performed for us is as our 'unofficial accountability mechanism'. He has taken the 'if-not, why-not' approach to

AusAID submissions or proposals that go up for his approval. If they haven't included some sort of analysis around disability and what the issues are and how that body of work will support it, he often sends it back to be strengthened in this area. Now, we need to build in more organisational accountability mechanisms to shore up integration efforts.

The way forward

Unless AusAID knows what to do and they have the systems and support in place to work in a way that includes people with disability, we are not going to be able to change the way that the aid program works. We are currently undertaking a comprehensive staff survey to get an in-depth understanding, right across AusAID, of what people know about disability-inclusive development, what opinions are, what their attitudes are, what their prejudices are, how they are already doing this work in their core business and what would change their work? That information is not only going to provide us with a baseline of where we are at and how well we have done in changing AusAID, but it is going to inform our communication strategy, our capacity development and our leadership work with AusAID.

We also are in the early stages of developing a 'resource facility', which is a way of providing disability technical assistance to AusAID staff as they do their work. For example, during the design of a new education program it will appropriate technical support, preferably people with disability, who have skills to support them in those efforts.

We have recently appointed two regional specialists on disability-inclusive development who will be working with our country program in the regions to support this work, one in Asia and one in the Pacific. As I mentioned, getting accountability systems in place, AusAID's operational and business systems will be critical. We are about halfway through finalising a comprehensive performance assessment framework that will establish a baseline and give us the information that we need to monitor and test how the strategy is going and to be able to report back to all those involved and, obviously, the Australian Government. We also need to step up our work around education and infrastructure.

As the aid program doubles over the next five years it will be education and infrastructure that will be the flagships so there is huge scope to have an impact there, in terms of inclusive development. We are developing universal design guidelines in terms of infrastructure that we hope will be mandatory through all of AusAID's contracts on social infrastructure, road transport and a range of other infrastructure areas. The final key priority for next year is about improving our understanding of disability, poverty and development and getting our research strategy up and running, so we can better understand the barriers to access and participation for people with disability.

Key issues in the Pacific Regional Strategy on Disability 2010–2015

Fredrick Miller, Disability Coordination Officer,
Pacific Islands Forum Secretariat

An important move towards implementing the CRPD in the Pacific was the development, in 2010, of a five year Pacific Regional Strategy on Disability (PRSD) 2010–2015. It was developed under the auspices of the Pacific Islands Forum Secretariat. Its purpose was to:

- support Pacific Island Forum member countries to protect and promote the rights of people with disability;
- provide a framework for the coordination of development partners, governments and civil society in building a disability-inclusive Pacific; and
- strengthen commitment of all stakeholders towards implementation of the CRPD and other human rights instruments that relate to disability.

The Strategy identifies six themes:

- strengthening political leadership and an enabling environment;
- recognising and protecting the human rights of people with disability;
- strengthening partnerships among all stakeholders through coordination and collaboration;
- disability-inclusive development;
- enhancing the central role of people with disability;[1] and
- mobilisation of resources.

The process for developing the PRSD

In the development process of the PRSD the following points were noted:

1. People with disability represent an estimated 10 percent[2] of any population. This represents some 800,000 Pacific Island people. Recent census results and national surveys do not provide a clear and accurate picture of the situation of people with disability because there is not a clear and generally accepted definition of disability; surveys have often been based on small population samples; and questions are often unclear as enumerators are poorly trained on disability issues.[3]

2. There is a need to improve the quality research and data on the prevalence of disability and the issues affecting the lives of people with disability in the Pacific region.

3. The number of people with disability is increasing in the Pacific as a result of high rates of diabetes, increasing numbers of traffic and industrial accidents; increasing life expectancy and the lack of early identification, intervention and referral services.

4. People with disability and their families face prejudice, discrimination and rejection. Children with disability are consistently excluded from attending school — less than 10 per cent have access to any form of education with many not attending at any time in their life.[4] Health and welfare service provision is poor and largely inaccessible to people with disability and there are few employment opportunities. Where services exist, implementation tends to be ad hoc, uncoordinated and poorly funded. Most Pacific governments are not making provision for disability services and inclusive policies in their budgets.

5. People with disability in Pacific Island countries are among the poorest and most marginalised members of their communities. The link between disability and poverty and social exclusion is proven.[5] Disability is both a cause and consequence of poverty. Studies have shown that the traditional view in the Pacific is that people with disability are to be looked after or cared for and are not expected to take an active part in village community life, thus marginalising them.[6] This view of people with disability as dependent typifies a ‘charity’ or ‘welfare’ approach and is by no means unique to the Pacific. A widespread ‘medical’ approach sees disabilities as health impairments that can be cured. It is only in the last few decades that people with disability in any part of the world have been recognised as fully participating members of society.

6. Forum island countries are at different stages of development in regard to disability (UNESCAP 2010). Until relatively recently, the national disability agenda has been largely neglected. While many countries have clear rights-based policies, few have specific legislation. Many have active Disabled Persons Organisations (DPOs) that have lead the disability agenda in collaboration with governments. The role of DPOs has been central to the implementation of the Biwako Millennium Framework (BMF).

7. People with disability must be included in national development processes. Development of rights-based policy, legislation and service provision must be established in partnership with DPOs and other concerned agencies. People with disability have proven their capability to contribute to this process.

8. While some people with disability are becoming empowered, diversity among people with disability needs to be acknowledged and attention should be paid to marginalised groups — such as those with psychosocial disability, intellectual disability, multiple disabilities, women and youth and those living in rural and remote areas.

9. A recent UNDP study found that throughout both rural and urban areas in the Pacific, women and girls with disability face multiple and compounding forms of discrimination. Despite some 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, experience worse health outcomes and generally have lower social status.[7] Concern regarding women with disability is a priority area of the BMF and the CRPD.

Regional and international commitments of the PRSD

At the 2002 inter-governmental meeting to conclude the Asian and Pacific decade of disabled persons (1993–2002), governments, including those from Pacific Island countries, adopted the BMF for action towards an inclusive, barrier-free and rights-based society for people with disability in Asia and the Pacific. This builds on the agenda for action which guided the first decade. It outlines a set of principles, strategies, goals, targets, and directives for action and forms a comprehensive set of guidelines for countries to use in developing policies, planning and implementing programs for people with disability. While the BMF officially ends in 2012, its utility as a framework will remain.

At the 2003 Pacific Islands Forum, the leaders of Pacific Island countries endorsed the BMF as providing a set of goals for Pacific countries to work towards over the next 10 years.

Pacific Island leaders adopted the Pacific Plan in 2005. The overall emphasis of the plan is to create stronger and deeper links between the sovereign countries of the region. Disability progress and development is reflected in Initiative 12.5 and a disability desk has been set up in the Forum Secretariat for the purpose of coordinating the development and progress of disability initiatives in the forum island countries.

Leaders' support for PRSD

In 2009, Forum leaders reiterated their support for people with disability and reaffirmed the need for more attention to be directed to this disadvantaged group who are among the poorest and most vulnerable. They acknowledged that people with disability face many barriers to full participation in society. Leaders further noted that the regional disability strategy should address issues facing people with disability in the Pacific and to build awareness on the importance of greater access to more equitable opportunities to enhance their quality and full enjoyment of life — all inalienable human rights.

In 2010, a report on the Forum Disability Ministers meeting held in Cook Islands in October 2009 was endorsed by Forum leaders. It promoted an inclusive, barrier-free, and rights-based society for people with disability, embracing the diversity of Pacific people. Leaders supported the report's objectives to improve the lives and status of people with disability in the Pacific region and the need for disability-inclusive development in all government programs in Forum island countries to address the needs of people with disability, accepting that such people are among the poorest and most vulnerable and face many barriers to full participation in society.

Leaders reaffirmed their strong support for the Pacific Regional Strategy on Disability endorsed by disability ministers. The leaders agreed to:

- support Pacific Island forum member countries to protect and promote the rights of people with disability;
- provide a framework for the coordination of development partners, governments and civil society in building a disability-inclusive Pacific; and
- strengthen commitment of all stakeholders towards implementation of the CRPD and other human rights instruments relating to disability.

The PRSD reflects the reality and needs of the Pacific and its unique social, economic and geographic context. The strategy represents common agreement on how to proceed and a means for sharing experiences and practices. Leaders agreed that the strategy provides effective guidance to forum members in advancing their work on disability issues and a platform for engaging with governments on disability-inclusive development and progress at national and regional levels.

Including disability as a human rights issue in the PRSD

The rights-based approach outlined in the CPRD represents a paradigm shift from earlier charity or medical models. The rights of people with disability and their participation are central to this approach. People with disability have argued that their ability to function as full and active citizens in a modern society is limited not by their disability but by society's failure to recognise them and accommodate their needs. This is reflected in the PRSD.

Disability is an issue that lends itself to a regional approach. The PRSD reflects the reality and needs of the Pacific and its unique social, economic and geographic context. It represents a common agreement on how to progress and a means for sharing experience and practice, while it was designed to provide guidance to PICs in advancing their work in disability. It enables the Forum Secretariat's regional organisations to develop partners and civil society a platform for engaging with governments on disability-inclusive development and progress at the national and regional level. Individual Forum island countries, especially small island states, have neither the capacity nor expertise to develop policy legislation and programs, thus support from regional sources is critical.

The BMF and Biwako Plus Five provided regional mechanisms to assist countries to address national priorities for people with disability. The PRSD will provide a similar tool to assist countries to set national priorities to address the articles of the CRPD.

The Strategy identifies thematic areas that would most effectively advance the rights of Pacific people with disability and ensure their participation in national development processes. The proposed thematic areas are those that can be realistically addressed by countries. Under each thematic area are selected indicative areas for actions designed to provide guidance to countries in regard to how they might address their own priorities and commitments. These activities are also to facilitate coordination with other regional frameworks, such as the Pacific Education Development Framework (PEDF), which includes inclusive education as a cross-cutting theme.[8]

Implementation, monitoring and evaluation of PRSD

The PRSD will be implemented by governments over a five year period 2010 to 2015 — in collaboration with civil society, regional stakeholders and development partners. An implementation plan will be developed in consultation with stakeholders and a monitoring and evaluation framework will also be developed once the PRSD itself has been endorsed by ministers. Strategy targets will be linked to regional and international commitments to the BMF and the CRPD.

Regular reviews over the life of the strategy will be undertaken to monitor progress and implementation and to identify policy gaps and resource constraints.

The Pacific Islands Forum Secretariat has engaged ESCAP to draw up a detailed action plan, monitoring and evaluation framework for the PRSD. It is envisaged that there will be two focal meetings and two ministerial meetings between 2011 and 2015. The action plan will detail the total funding budget for these meetings and will advise the Disability-inclusive Development Team in AusAID through the normal PIFS processes.

References

UNESCAP (United Nations Economic and Social Commission for Asia and the Pacific) ‘Disability at a glance 2010: A profile of 36 countries and areas in Asia and the Pacific’, Social Development Division, http://www.unescap.org/publications/detail.asp?id=1407, accessed 5 February 2011.

World Bank 2007, *Social analysis and disability: A guidance note incorporating disability-inclusive development into bank-supported projects*, Social Development Department and Social Protection, Disability and Development Team, The World Bank, Washington DC.

Notes

1 ‘Nothing about us without us’ is the motto of people with disability, first coined by Disabled Peoples’ International which speaks to the human rights of each person to determine his or her own fate.

2 World Bank estimate as cited in ‘Social analysis and disability: A guidance note’, 2007, 6.

3 For example Inclusion International carried out surveys in Kiribati in 2003–2004 and identified 4.36 per cent of the population as living with a disability; while another survey in the island of ‘Eua in Tonga in 2007, showed a percentage of 13 per cent. A similar survey in Samoa revealed an incidence of disability of 2.2 per cent. The 1996 Fiji census included a question on disability and the 12,000 or 2 per cent of the population identified as having a disability.

4 Pacific Islands Forum Secretariat, ‘Issues in basic education for children and youth with disabilities’, paper for 2002 Forum education ministers meeting.

5 UNOCHR and IPU ‘From exclusion to equality: Realising the rights of persons with disabilities’, 2007, 1; ILO ‘Achieving equal employment for people with disabilities through legislation guidelines’, 2004, 1; Fiji Poverty Report 1997, Government of Fiji and UNDP, 55 and 65.

6 McKinstry G, Price P, and Macanawai S 2004, ‘A review of policy and legislation on disability in the Pacific’, Pacific Islands Forum Secretariat and Nowland-Foreman G and Stubbs D 2005, ‘Free and equal: A review of NZAID Pacific regional disability programme for the New Zealand Agency for International Development.’

7 UNDP Pacific Centre, 2009, ‘Pacific sisters with disabilities: At the intersection of discrimination’.

8 Other regional strategies include the Digital Strategy; the Pacific Platform for Women; the Pacific Regional HIV Strategy; the Forum Economic Ministers Action Plan etc.

An overview of progress from a Southeast Asian perspective

Saowalak Thongkuay, Disabled Peoples' International Asia Pacific

Background

Almost 60 per cent of the world's 650 million people with disability live in Asia and the Pacific (UNESCAP 2008). These 400 million people with disability in the region need support to achieve their basic rights. Differences in definitions of disability, methods of data collection and capacity of professionals collecting data prevent a more definitive number of people with disability in Asia, the Pacific and the rest of the world (Groce 2008). Some countries give low priority to people with disability resulting in their exclusion from official data.

Data from the Asia-Pacific Development Center on Disability (APCD) provide approximate numbers of people with disability in some countries of the Association of Southeast Asian Nations (ASEAN).

Table 1: Estimated numbers of people with disability in ASEAN countries

Country	Estimate No. of people with disability
Brunei Darussalam*	30,000
Cambodia*	554,000
Indonesia	6,000,000
Lao PDR	52,200
Malaysia	139,000
Myanmar	2% of the population
Singapore*	759,000
The Philippines	942,098
Thailand	1,100,762
Viet Nam	4,039,241

**Sources:* Disability information resources (Darussalam) <http://www.dinf.ne.jp/doc/english/intl/02rnn/dsfad_e.html> (accessed online 5 February 2011); Phillipa Thomas 2005 (Cambodia); Satyender Singh Yadav 2001 (Singapore).

Available data reveal wide disparities in the proportion of people with disability in Asia and the Pacific region, ranging from 0.7 per cent in the Cook Islands to 20 per cent in Australia (UNESCAP 2008). They report that many cases of disability in developing countries are caused by inadequate maternal and childhood nutrition, infection and disease, lack of clean water, accidents, armed conflict, terrorism and antipersonnel landmines. Seventeen per cent of Afghans are disabled because of armed conflict. In Cambodia, 18 per cent of people with disability are amputees caused by landmines.[1] In countries experiencing fast-paced globalisation with competition and higher levels of stress the number of people with psychosocial disability is rising. Conflicts and natural disasters have also contributed to this increase.

Poverty and marginalisation characterise the lives of the majority of people with disability in the region. UNESCAP considers people with disability to be 'among the poorest of the poor and the most marginalised in society.' Living mostly in the rural areas, they have difficulty accessing facilities which are usually located in the cities. They generally have limited access to education, employment, housing, transportation, health services and recreation, leading to their economic and social exclusion. The International Labour Organization (ILO) states that the unemployment rate among people with disability is usually double that of the general population and often as high as 80 per cent. They face frequent and diverse barriers such as negative attitudes of employers, lack of accessible facilities, lack of vocational and technical trainings.

Women and girls with disability in developing countries face triple discrimination due to their status as females, people with disability, and their over-representation among the poor. They are two to three times more likely to be victims of physical and sexual abuse at home or in institutions for people with disability. Few victims ever file a grievance due to lack of confidence and knowledge of where or whom to turn for help.

Children with disability are largely excluded from educational opportunities. It is estimated that the majority of countries in the region have less than 10 per cent of children with disability enrolled in school. The UNESCAP Survey in 2004 indicates for example that the school enrolment rate of children with disability is 2 per cent in the Philippines and 4 per cent in Bangladesh and Pakistan.

Regional response

The UN World Programme of Action concerning disabled persons provided a framework for addressing disability. It entails 'long-term strategies integrated into national policies for socio-economic development, preventive activities that would include development and use of technology for the prevention of disability, and legislation eliminating discrimination regarding access to facilities, social security, education and employment'. UNESCAP followed this up with the first regional decade on the issue, 'The Asia Pacific Decade of Persons with Disabilities, 1993–2002' (UNESCAP 2007). This decade aimed at strengthening regional support for the implementation of the World Programme in the Asia–Pacific region beyond 1992, and strengthening regional cooperation to resolve issues affecting the achievement of the goals of the World Programme, especially full participation and equality of people with disability.

An Agenda for Action, subsequently adopted to implement the decade of persons with disabilities requested all members to support its national implementation through public awareness activities, appropriate policies and other measures, and the allocation of resources. All governments, donor agencies and the private sector were invited to contribute to the trust fund for the decade to ensure the successful implementation of the agenda for action. UNDP, UNICEF and other concerned UN bodies and agencies were invited, with ESCAP, to strengthen their support for building of national capabilities to effectively implement the Agenda.

Two regional meetings in 1999, in close collaboration with disability-related stakeholders, developed practical guidelines for equal access by people with disability to mainstream development opportunities in:

- education and technology for the specific needs of children and youth with disability;
- implementation of the UN standard rules on the equalisation of opportunities for people with disability; and
- fulfillment of the decade targets.

In May 2002 UNESCAP extended the decade of persons with disabilities for another ten years from 2003 to 2012 and started a number of initiatives. In October 2002, a high-level inter-governmental meeting held in Otsu, Shiga, Japan adopted as a guideline for action the 'Biwako Millennium Framework for Action towards an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific' (BMF). The BMF promotes a paradigm shift from a charity-based to a rights-based approach to disability. It promotes a barrier-free, inclusive and rights-based society, which embraces the diversity of all human beings. It further enables and advances the socioeconomic contribution of its members and ensures the realisation of those rights by people with disability. The BMF incorporates the MDGs and their relevant targets to ensure the concerns of people with disability are part of MDG and national poverty alleviation strategies.

Many global and regional efforts have promoted the rights and equal opportunity of individuals with disability. With the ultimate goal of mainstreaming people with disability in development, the ASEAN Ministerial Meeting on Social Welfare and Development called for the inclusion of concerns and experiences of people with disability as an integral dimension of policies and regulations in all spheres of the ASEAN community. This is to ensure that all those living with disability are given equal opportunity and access to the employment market (ASEAN 2007).

Challenges to progress in Southeast Asia[2]

The founding document of the Association of Southeast Asian Nations called for 'partnership in order to strengthen the foundation for a prosperous and peaceful community of Southeast Asian Nations'. This established parallel efforts to formulate and carry out plans of action towards constructing close political, economic and socio-cultural communities to ensure durable, stable, secure and shared prosperity in the region.

To have an effective socio-cultural community, the purposes, activities and achievements of ASEAN need to communicate to the peoples of Southeast Asia. To this end, engagement and empowerment with think tanks, professional organisations, academic institutions, the scientific community, humanitarians and first responders, the private sector, and other development groups committed to the ideals and purposes of an ASEAN Community are important. Grassroots, NGOs and civil society organisations are instrumental in bringing the ideals, spirit and message of ASEAN to their respective communities who should be encouraged to continue to strive and pursue their independence and means of contributing to the ASEAN community.

A joint communiqué of the sixth ASEAN Ministerial Meeting for Social Welfare and Development in Ha Noi, 6 December 2007, stated that inclusive, barrier-free and rights-based societies for people with disability are needed due to the effects of globalisation and rapid social and economic changes that contribute to the complexity of challenges that affect human security, further marginalising people with disability. With the ultimate goal of 'mainstreaming persons with disability in development', committees commended the inclusion of concerns and experiences of people with disability as an integral dimension of policies and regulations in all spheres of society to ensure that all those living with disability are given equal opportunity and access to the employment market (ASEAN 2007).

The establishment of an ASEAN Persons with Disabilities Forum will play a leading role in the promotion, protection, networking and collaboration among government, civil society organisations and DPOs. The Forum will continue to undertake cooperation in people-to-people interactions, cultural tourism, academic exchanges, promotion and protection of human rights and social justice of vulnerable groups, women, children and exchange with ASEAN nations through broadcast, print and electronic media.

The Millennium Development Goals

The MDGs eight goals and 17 specific targets, from halving the proportion of people living below the poverty line to halving the proportion of people without sustainable access to resources, promote social inclusive in development. These are also some of the mandates of ASEAN in achieving enduring solidarity and unity among ASEAN nations and peoples by forging a common identity and building a caring and sharing society which is inclusive and harmonious enhancing the well-being, livelihood, and welfare of its peoples.

Summary

The ASEAN Strategic Framework 2011–2015 on Disability has three thematic priority areas:

- a decade of people with disability towards an inclusive ASEAN community;
- promoting inclusive social development; and
- advancing ICTs/AT and media for people with disability.

The Framework aims to establish a people-oriented inclusive ASEAN Community and:

- mainstream disability perspectives in ASEAN mechanisms in order to promote and protect the rights of people with disability;
- mainstream and advance inclusive education and decent work of people with disability through inclusive social development;
- promote capacity-building of central/local government and DPOs, as well as civil society in promotion and protection of the rights of people with disability; and
- promote information and communication accessibility through enhancing ICT literacy of people with disability as well as research and development of accessible and assistive technologies for people with disability.

References

ASEAN 2007, Joint communiqué of the Sixth ASEAN Ministerial Meeting for Social Welfare and Development, Ha Noi, 6 December 2007, http://www.aseansec.org/21221.htm, accessed 5 February 2011.

Disability Information resources (DINF), Disability statistics before and during the first Asian and Pacific Decade of Disabled Persons 1993–2002, http://www.dinf.ne.jp/ doc/english/intl/ 02rnn/dsfad_e.html, accessed 4 February 2011.

ESCAP 2002, Resolution 58/4, 22 May 2002, *www.unescap.org/ EDC/English/Resolutions/2003(59).pdf*, accessed 5 February 2011.

Groce NE 2008, Fifth quinquennial review and appraisal of the World Programme of Action concerning disabled persons: Report of the Secretary-General (Secretary-General's Reports 63rd session 2008-2009, A/63/183). United Nations: New York, US, http://www.un.org/disabilities/default.asp?id=1472, accessed 4 February 2011.

Thomas P 2005, 'Poverty reduction and development in Cambodia: Enabling disabled people to play a role', Disability Knowledge and Research Programme, http://www.healthlink.org.uk/projects/disability/kar_thematic.html, accessed 5 February 2011.

UN Convention on the Rights of Persons with Disabilities (CRPD) 2008, http://www.un.org/disabilities/default.asp?navid=14&pid =156, accessed 5 February 2011.

UNESCAP (United Nations Economic and Social Commission for Asia and the Pacific) 2007, 'Biwako plus five: Further efforts towards an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific', Intergovernmental meeting on the midpoint review of the Asian and Pacific decade of disabled persons, 2003–2012, E/ESCAP/APDDP(2)/2, http://www.unescap.org/esid/psis/ Disability/bmf/APDDP2_2E.pdf, accessed 5 February 2011.

UNESCAP (United Nations Economic and Social Commission for Asia and the Pacific) 2008, Disability Fact Sheet, http://www.unescap.org/esid/psis/FactSheets.pdf, accessed 4 February 2011.

UNDP (United Nations Development Programme), Millenium Development Goals, http://www.undp.org/mdg/goal5.shtml, accessed 5 February 2011.

Yadav S 2001, 'Disability and Handicap among elderly Singaporeans', Singapore Med J, 42(8), 360–367.

Notes

[1] See Cambodia country profile, http://apcdproject.org/ country profile/cambodia/cambodia.html.

[2] Revised from 'Constructing the social pillar of the ASEAN community', comments by MC Abad, Jr., Director, ASEAN Secretariat, at the 21st Asia Pacific Roundtable, 4–8 June 2007, Kuala Lumpur.

Conventions, strategies and plans: Pacific and Asian country perspectives and action using conventions for disability-inclusive action in the Pacific

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What do the words in the title of this paper actually mean? Are they important? And does it matter that we all use these words to mean the same thing?

There's a famous discussion about what words mean in Lewis Carrol's *Through the Looking Glass* — the book that followed Alice's Adventures in Wonderland. Humpty Dumpty uses everyday words in sentences in a way that Alice doesn't understand. When she tells him this, he says 'Of course you don't — till I tell you. When I use a word it means just what I choose it to mean — neither more nor less.'

Words like 'using Conventions for disability-inclusive action' can mean different things to different individuals and groups — people with disability, disabled people's organisations, governments, funding organisations, and the development sector. This lack of common understanding can lead to confusion and frustration, to valuable resources being wasted and opportunities for rapid and effective progress being missed, and to the rights of people with disability continuing to be violated, abused and neglected.

But where there is common understanding of meaning, disability-inclusive action that is guided by Conventions, there is the beginning of real and effective change. Actions are being framed from the perspective of people with disability, and their having a real say in what needs to be done.

Convention on the Rights of Persons with Disabilities

I deal mainly with the Convention on the Rights of Persons with Disabilities, or the *DisCo*, although it is important to remember that other rights-based conventions also apply to people with disability. These are:

- the human rights covenants on civil, political, economic, social and cultural rights
- the Conventions on the elimination of racial discrimination and discrimination against women
- the Convention on the Rights of the Child
- and the Convention against Torture and Cruel Inhuman or Degrading Treatment.

Why do we need the *DisCo* in addition to the rest, you may well ask. And why is it so important? First, because it puts the spotlight on disability in a way that earlier conventions failed to do. Legally, people with disability should always have been covered by rights applied to all individuals and prohibitions against any discrimination. Failing to mention disability at all has prevented the realising of human rights for people with disability in practice, or doing anything useful and effective towards making it happen. Among the major conventions, only *DisCo* and the Convention on the Rights of the Child actually mention disability.

In the real world, as soon as we remember to look, we see that 'all individuals' includes at least ten per cent of people with disability. We see that 'any discrimination' includes daily discrimination on the basis of disability: in lack of physical and information access, in social systems, attitudes, and expectations of what people can and can't do. And we see that people with disability experience social exclusion and are heavily represented among the most disadvantaged. We see that the link between disability and disadvantage applies in any other area of disadvantage we look at. Women with disability, for example, experience extra dimensions of disadvantage, exclusion and abuse of human rights compared to other women, and compared to other people with disability.

Here are some comments from Marian, one of the participants in the disability rights workshops we've been conducting, together with the Pacific Disability Forum and other regional partners:

> *Marian (Vanuatu)*
>
> *We have some custom beliefs that women are not going for a successful education, only boys, because if woman goes, then their parents say that if a man marry her they will waste their money to buy a school for a woman. So what I did, I have to go and tell them their rights, tell them their rights and support them. Like for example, if the man said 'you are not allowed to go any place!' or 'you are not allowed to stand up and talk', I have to say 'we have the right to talk'. So what I support them in is I have to come and stand near them and say 'you have to say something!' So now I find the response that some women are not talking at all, like they are worst, lock up, but now they've started to stand up. So I was very proud of the small thoughts that I have. I have said to the other ones, it helped them fully. And sometimes, when their husbands abused them, I have to talk to them and said 'you have to go to the office to see the ladies that are responsible for helping us in violence', then they have to go out. Otherwise, I stand on my two feet to go and see the police and say 'these things are not good'. So this is why the ladies in my area see the example that I did. They find out that it is true, we have the same rights as the other ones. So we women can do something, we women can go out, we women can talk out or we can move any places. So now they were very happy. We found out that in my village or in my area, there is light, that everyone enjoy the nature. That everyone is happy because we share inside the community, we share the activities or we participate in the program that are included in our areas, or in town, or in the national level. So I was very proud to say that now we are improving.*

It is also plain that there are multiple issues of disadvantage and exclusion for children with disability, for people with disability in Indigenous communities, or people in rural and remote areas. The same is true for people with d isability in societies with acute development needs and higher levels of poverty. The failure of earlier conventions to recognise these realities has contributed to human rights not being central to the efforts of governments, development agencies, and funding bodies in the past.

Too much human rights discussion occurs as if human rights are about individual legal rights and not social change. The *Disco* is a welcome and overdue antidote to that sort of thinking.

An agenda for social change

This brings me to my second set of reasons why the *DisCo* is important. More clearly than any previous convention, *DisCo* sets out a series of agendas for social change and a set of actions to get that change happening. It is more than just a passive requirement to respect human rights, or a general obligation to take all appropriate measures to realise human rights. It is a detailed and extensive list of things to do.

In the development of *DisCo* there was much argument about whether we needed a convention on human rights and equality, or a convention on disability, development and social change. What we got is both — a human rights and a development convention.

Here in Australia, we are already seeing the impact of the two features. We have a draft National Disability Strategy, expressly framed as a strategy for implementation of the convention, including reporting against a set of indicators for social change. It's exciting to see that around the region there are similar moves towards national disability strategies, focusing on rights and obligations as set out in the convention as key to development strategies for social change.

This brings me back to the Humpty Dumpty question. What do we mean by disability inclusive action, and disability inclusive strategies? We could just mean action by governments, and other powerful and hopefully well meaning actors, to promote inclusion for people with disability. But that is not the agenda *DisCo* presents.

Critically, the Convention places people with disability and organisations that represent us at the core of any action. This is clearly stated in Article 4, and throughout the Convention.

Here is another voice of experience:

Elenoa (Fiji)

> *I have learnt some of the things that we need to do in order to work with government, the necessary things that women with disabilities can contribute to government. Because as women with disabilities I believe that we are experts in our own issues, and we are the only ones that can. Unless they see us advocating for our own issues they will never understand about disability. One thing I always tell people is that disability is about experience. It's not just what you learn in the books, but the most important thing is experience. To advocate for the rights of people with disabilities, especially for women, you need to be a woman with a disability, or to be someone who is dealing with a person with a disability. Because you cannot teach someone your experience. You can just share and they can learn from it. That's from my own point of view. And it is very important for us to contribute to what our views to government because they make laws and legislations. And those are the things that will make changes to our own countries.*

Governments, and others involved in making decisions about social development, need to consult with people with disability. This is because the Convention says so and people with disability and their organisations possess knowledge and experience essential to governments and development agencies. It is really important to remember that *DisCo* is not just about disability services or policy, or human rights, but about transport, building regulation, communications, education, government administration, employment policy, etc.

Here is a third voice of experience:

Marjorie (Cook Islands)

> *I think it is important for government to listen to people with disabilities because there are some workers in governments, there are some things that they don't know. They can't see what disability people are feeling. Because some disability people… they are too scared to voice their voice… in order for people to listen to them. Because I know it is culture here in the Cook Islands for us little people to respect older people, or to respect highly ranked people. So it's kind of like not having the freedom to express your own opinion on what you want, or the issues that you are facing. And this I urge the government to maybe include some disability people when deciding amongst themselves in what needs to be done. Because over the past few years I have been listening to parliamentary talking on radio … they're mostly focusing on some other things, some other issues. Maybe it's time they should consider bringing disability people into the meeting and ask them what are they thinking about. What kind of troubles they are facing. And then from there they can work their way up, in order to progress the disability people's centre or group in the Cook Islands.*

It is obvious that Marjorie's statements are not just about the Cook Islands. They are true everywhere. Exclusion of people with disability has meant that we have not been able to share our experiences effectively enough or to indicate to the change makers what needs to be done. Disability is not understood, or is understood narrowly, by governments, service providers and funding and development agencies — even by human rights organisations.

Conclusions

Finally, I want to make some blunt statements.

- Because of the history of social exclusion of people with disability, governments in all societies do not have the necessary understanding of the experience or needs of people with disability.

- Despite the richness of expertise available in the disability community, our social and economic exclusion has limited us and our organisations. We cannot yet provide the input that governments need.
- Effective development and compliance with *DisCo*, requires urgent action to empower people with disability, strengthening capacity of their organisations.
- To achieve rights and to ensure dignity and respect, we must always use the language of rights.

There are some very big challenges in all of this. Each of us, in our own organisations, has much to do to measure up to those challenges. But *DisCo* allows us to see what inclusive societies would be like. Our challenge is to change wonderland into reality.

Developing, negotiating and implementing a National Disability Strategy for Papua New Guinea: Lessons learned

*The Hon. Dame Carol Kidu, MP, Minister for Community Development, Religion and Sport,
Government of Papua New Guinea*

Introduction

I want to start with something I have found from my own experience. This is as a team, together, everyone achieves more.

Over the last 10 years there has been a lot of progress in Papua New Guinea (PNG) but there is still a long way to go to achieve inclusive development for people with disability and to expand our disability coverage. For example, we have nothing to help victims of burns; we have nothing to cover emotional and psychological well-being of our people as they cope with the interface between tradition and modernity and the trauma that creates. There are many things not included in our disability movement.

The key to the success in the last decade has been because of strong bureaucratic and Disabled People's Organisation (DPO) leadership including the Secretary of our Ministry and his senior officer, and Ipul Powaseu, President of the PNG Assembly of Disabled Persons. Success has been the result of strong leadership and working in close partnership with civil society, service providers and development partners.

Government's role in disability

In PNG, the statutory responsibility for disability lies in the department that I head, the Department for Community Development. The Departments of Education and Health also have staff to implement their policies relevant to special needs for disability, such as inclusive education, but there is a real need for us to keep pushing for disability to be mainstreamed. It needs to have a mainstream function in government policies, as well as its own specific policy framework. Some work has been achieved by the Department of Labour as they work to remove discrimination in labour laws and policies. We now need to broaden this to all departments. The Department for Community Development has reviewed its structure and increased staffing to facilitate disability policy implementation.

The government, through the ministry and bureaucracy, recognises the PNG Assembly of Disabled Persons (ADP) as the umbrella DPO. This recognition is affirmed with the Government's commitment to strengthen the capacity of ADP, and if we can convince the people who control our budget, to increase it more progressively. ADP are the ones with the link on the ground. They are the ones who are the real stakeholders and they will implement most effectively.

Financing for disability inclusion

The Department's recurrent budget for disability has increased. When I became minister, there was a recurrent budget, but absolutely no development budget. Literally, not one *toya* — that is equivalent to one cent. There was only a recurrent budget. But now, that the recurrent budget is gradually increasing and we allocate about half of it, if we can, to self-help organisations and disability service providers.

In 2002, there was no development budget and no policy, and I soon learned, as a very inexperienced minister, that no policy meant no money. So that is why we are moving quickly to work on a policy.

Disability is what we call a decentralised function in PNG. We are responsible at national level for legislation, policy, international linkages and programming. But, really, it is a decentralised function. There is a problem in that most provincial and district budgets do not cater for disability. But, as we keep our determined policy roll-out and our increased consultation between the levels of government, we hope that this will improve.

Government is now working on a social protection policy with a team from many departments. The team includes disability, which has been identified as a most vulnerable group in PNG. It will be the end of 2011 before we will have an endorsed policy. Right now, we are in the draft and research stage.

Disability policy development in PNG

So what has happened with policy development in Papua New Guinea? In the 1990s, there was a national plan for the prevention of disability and the integration of people with disability into national development. In 2001, National Government asked for assistance from UNESCAP to develop a national policy on disability. I became minister in 2002. I came in at a time when there was going to be some technical assistance coming to the department. For over six years, government officers and stakeholders engaged in dialogue and consultation to develop the policy based on the Biwako Millennium Framework principles. Eventually, in April 2008, our National Executive Council, or what is called Cabinet, approved the PNG National Policy on Disability, and we officially launched it in July 2009.

The vision of the policy is to build a compassionate and family-based society that recognises that people with disability have the same human rights as others and that there are no physical or social barriers or attitudes that limit their full participation in everyday life. A wonderful, lofty statement! But we must start with wonderful lofty statements. It is a lot to achieve for the majority of people in PNG.

The policy goals are to promote and create awareness and to build rights and a barrier-free inclusive society. They are to be achieved through 11 targeted policy priorities which are to be the point of reference and guide for future plans, programs, research, etc, on inclusive and enabling environments for disability.

The policy identifies the following 11 priority areas for action:

- dietary information;
- national coordination;
- legislation;
- public awareness;
- self-help organisations, provincial associations;
- prevention, early detection and intervention;
- rehabilitation services and assistive devices;
- education, training and employment;
- disability and communication; and
- social security and livelihood and gender equity.

We want any development assistance and/or research to focus on these priority areas as identified by the PNG/ADP and the department. Increased government action and increased budget commitment combined with wide participatory consultation have resulted in increased activity and support from NGO and church service providers and from the PNG ADP.

Working together in partnership

In the past there was little relationship between government, the NGOs and civil society but getting the policy in place has strengthened the partnership between civil society and government, and I hope that that will continue because civil society are the implementation partners for government. In government we do not have the human work power, or the financial resources to implement. We rely on our service providers.

Connecting government with the people through a human rights approach to inclusive development is not an easy task in PNG with remoteness and a multitude of languages. So we need to really focus on the community level. Doing lots of good work at the national level is not going to improve things for the people on the ground in PNG, because it is a very long journey. It's a very long journey from the International Convention, at the top of the triangle, through the national strategic plans and policies right down through the integrated local development plans and activities. There are many barriers in the way. So it is important that to maximise our limited resources, we ask that NGOs and any organisations working in communities should relate to this journey — to integrate with the policy, and not work in isolation of government, because we know how limited we are.

We are keen, we have extremely good officers, but we don't have a lot or enough funding. So we ask for partnership. Then the big challenge is, of course, to take it from rhetoric to reality. The National Policy on Disability is a community-based policy, and it is based within an umbrella policy framework called the Integrated Community Development Policy, another new overarching policy of how we can grow our communities from inside out, from the bottom up, not just paying lip service to bottom-up planning.

Policy documents are meant for people, not government. They must be developed by people, with people, for people through meaningful consultation. Our challenge is to translate the international conventions and national policies into a changed reality for people through funded and resourced programs. But the journey to reach our people in PNG, with over 820 distinct languages and isolated communities, where you walk six or seven days from a small airstrip to reach a community, is long, complex and sometimes overwhelming — and you think, 'How can we do it?' So we need strong, well structured and genuinely integrated partnerships to make it happen.

There is a real power in partnerships. In PNG, it is very important, I believe, for politicians to actively help to facilitate the partnerships. We need to focus on this community bottom-up approach. We need to keep strengthening national development. Leadership from both Government and the PNG/ADM must continue. But, at the same time, we have to focus at the bottom and find ways to include that connection.

We must take ownership, and then we invite our development partners, our international agencies, our private sector, and our research agencies to come from outside-in and to help us in our task. If we don't take ownership, we have missed the boat, and I think we will not be sustainable.

The WOG and WOS approaches

I have got the WOG — and the WOS approach is needed. WOG stands for whole of government — every government agency must see their responsibility. WOS stands for whole of society.

Traditionally, people with disability were part of the community — it was a whole of society part of their lives and they were defined not as people with disability, but according to their impairment. I think it is very important for me as a politician to always remind myself that laws, policies and structural reform which I have become obsessed with are not enough, even when they become institutionalised in a strong democracy.

Laws and policies alone will not change reality for people with disability, even with an efficient bureaucracy, and our bureaucracy has become weakened by many factors, including brain drain, so we struggle with loss of human resources because people want to find better opportunities for their children than those available working for government. That is why I respect my bureaucrats and the way they work.

In the final outcome, the solutions to the challenges begin and end in civil society and in our communities, not in the laws and policies. They give the frameworks.

Using an OPEN strategy

The key for sustainably inclusive development must be in the community. Our families' communities must have access to opportunities, knowledge, skills transfer, to take ownership of their development and build these inclusive communities from inside-out, using what we have called in our department an open strategy. Build from, but enhance, traditional inclusion.

The open strategy — OPEN — worked out by one of the communities in my electorate.

O stands for ownership in our self-help organisation;

P for participation and partnerships;

E for empowering and enabling environments; and

N for networking and sharing experiences.

It is so easy in our lofty towers in capital cities, in the chambers of parliament, to lose track of the importance of that — the OPEN strategy.

Challenges into the future

In summary, where we are going? We have developed the policy, we have established the National Advisory Council. We have established the PNG/ADP. We have hundreds of self-help organisations affiliated upwards. The department is collaborating with agencies to collect data, and we have ongoing public awareness. The awareness on the CRPD consultation with major Government agencies was on October 2008 and the strategic planning workshop and inter-departmental meeting in October 2009. We now have the submission ready for signing the CRPD. We are celebrating PNG National Disability Day in March with a keynote address, with Professor Ron McCullum and the committee.

Our challenges include staff capacity — we have a good staff, but we need technical aid from development partners for legal work and we need ongoing awareness and advocacy on public action. We need to keep lobbying and being accountable and transparent when we get money for our providers. And we need to partner with the National Statistics Office on data.

We lack specialised people in the area of disability. Two VSOs have just finished their time here and we have two newly recruited AVRs. We are working towards specific legislation and aggressive implementation.

Officially, there is no disability in PNG. Disability is not in the MDGs so we tend to be competing for funding and attention. It must get into the MDGs. We have a canoe, MDGs have a canoe. The four people are paddling frantically, but two in one direction and two in another. This often happens in PNG. We must learn to paddle in the same direction to create an inclusive barrier-free PNG through consultation and better coordination, and we need lots more networking and learning from each other.

The Convention on the Rights of Persons with Disabilities: A methodology for collaboration in capacity building and research

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The General Assembly of the United Nations adopted the CRPD and its associated optional protocol on December 13, 2006. At its opening ceremony on March 30, 2007, Australia with 80 other nations and the European Union signed the CRPD. The Convention entered into force on May 3, 2009. The CRPD negotiations are reputed to have involved the highest level of civil society participation of any human rights treaty with overwhelming representation of people with disability and disabled people's organisations (DPOs), including representatives from developing countries across Asia, Africa and the Pacific.

This paper examines CRPD and the mechanisms it contains to promote and foster capacity building, in particular research and engagement of people with disability. It briefly introduces some of the innovative elements of CRPD and then outlines the way the Convention develops a normative framework for disability research and considers the integral role people with disability should have in the research process. It also recognises the critical role of capacity building in achieving compliance to the CRPD.

Formation and function of the CRPD

The adoption of the CRPD is a significant legal and policy advance, moving from non-binding international standards to formally binding legal obligations for those states that become party to the Convention. The Convention was intended to build on existing human rights standards and apply them within a disability context to ensure that people with disability can exercise and enjoy all of the fundamental human rights and freedoms. Some rights are simply restated in the form in which they appear in other documents, for example, the right to life, but most contain detailed content to provide a clearer understanding of the obligations required to comply in order to fulfil the right. The CRPD is effectively an international charter of rights for people with disability.

Central to calls for a thematic Convention on disability was the failure of the existing framework of non-binding instruments to have a significant impact on many of the world's people with disability. The strength of a Convention was seen to be in the binding nature of the obligations on states and the legal rights it accords people with disability. This relationship between states and their citizens means compliance through domestic implementation is an essential feature.

Various developments in soft law had provided a significant framework of principles but had not necessarily delivered reform and social change. The normative nature of such an instrument means compliance is fundamental and that domestic application and implementation are essential goals. The binding nature gives credibility to the intentions of states and clearly establishes a role for international and national governance.

It has been suggested that the emphasis should be on management of compliance, not the enforcement of obligations. Commentators contend that the principal source of noncompliance is not wilful disobedience but the lack of capacity, clarity or priority, hence the notion of enforcement is a misguided means to achieve compliance. What is needed is a sophisticated strategy to directly address these three deficiencies in dealing with compliance issues. Strategies that include such elements as transparency and capacity building are more effective in generating compliance. Greater emphasis should be placed on implementation strategies, transparency and capacity building. Transparency, the generation and dissemination of information about the requirements of the treaty regime and the parties' performance, is an almost universal element of management strategy. Transparency influences strategic interaction among key stakeholders in the direction of compliance. Capacity building is aimed at addressing deficits of technical and bureaucratic capability and policy resources.

The very nature of disability and the inherent systemic discrimination and social exclusion that is part of disability means that many governments have very limited expertise in disability. Historically, people with disability have been excluded from key social institutions which isolated them and issued raised by disability raises in mainstream public policy. This has been repeatedly demonstrated through the failure of successive treaties to identify disability as an area of concern. The active participation of people with disability and their representative organisations in public policy processes is central to building capacity.

The CRPD and human rights

In recognising the critical role of capacity building in achieving compliance, this paper examines the CRPD and the mechanisms it contains to promote and foster capacity building, in particular research and engagement of people with disability. It introduces some of the innovative elements and outlines the way the Convention develops a normative framework for disability research and considers the integral role of people with disability should have in the research process. These innovations give greater insight to the obligations on states and a clearer understanding of how disability is to be understood. For the first time in an international instrument, the CRPD contains a list of general principles. These principles include:

- respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of people;

- non-discrimination;
- full and effective participation and inclusion in society;
- respect for difference and acceptance of people with disability as part of human diversity and humanity;
- equality of opportunity;
- accessibility;
- equality between men and women; and
- respect for the evolving capacities of children with disability and respect for the right of children with disability to preserve their identities.

These principles underpin the interpretation of the substantive articles and provide guidance to member states for implementation. Another innovative element is found in Articles 6 and 7, which set out general guarantees and recognition of particular population groups. In particular, Article 6 recognises that women and girls with disability are subject to multiple discrimination and places an obligation on states to take appropriate measures to ensure that women and girls with disability enjoy fundamental freedoms and human rights.

Perhaps the most innovative element of the Convention is found in Article 9, which introduces the concept of accessibility as a wide ranging right to ensure people with disability can participate fully in all aspects of life. It is this article that gives life to the principle of substantive equality. It ensures that states take measures to provide access on an equal basis with others to the physical environment, transportation, information and communication, and facilities and services openly provided to the public in both urban and rural areas. It is an overarching right aimed at guaranteeing equality of access for people with disability to all facilities and services within the community.

The Convention also incorporates four other formulations of rights, in brief:

- Article 11, situations of risk and humanitarian emergencies;
- Article 17, protecting the integrity of the person;
- Article 19, living independently and being part of the community; and
- Article 20, personal mobility.

The final novel element I wish to note is that for the first time in an international human rights treaty, the Convention also incorporates in a stand-alone article, Article 32, on international cooperation, which I will look at in more detail below.

Developed from a mandate not to introduce any new rights, CRPD and these innovations demonstrate that existing human rights look very different when viewed through the prism of disability and are meaningless in addressing disability issues without a clear understanding of the phenomenon of disability. Capacity building is critical in developing an understanding of the barriers confronting people with impairments in their daily life as basis for law and policy reform. CRPD incorporates several mechanisms to promote capacity building.

The CRPD and civil society

A major achievement for this Convention is the way that it successfully integrated ongoing involvement with civil society, in particular, people with disability. The CRPD is the first Convention to thoroughly engage civil society in negotiations and include substantive provisions outlining ongoing engagement with implementation and monitoring. These provisions are embedded in Article 4 General obligations and Article 33 National implementation and monitoring.

The CRPD and capacity building

The CPRD engages with people with disability as a central element of implementation and monitoring of the human rights and fundamental freedoms contained in the Convention. Embodied in the preamble, CRPD acknowledges that fundamentally 'people with disabilities should have the opportunity to be actively involved in decision making processes about policies and programs, including those directly concerning them'. This principle highlights the central role that people with disability should play in capacity building and as advocates for their rights. CRPD enshrines this principle within the substantive binding provisions of Article 4 – General obligations. Article 4(3) provides that in the development and implementation of legislation and policies to implement the Convention and in other decision making processes concerning issues related to people with disability states shall closely consult with and actively involve people with disability, including children with disability, through their representative organisations.

The CRPD embraces active dialogue with people with disability and their representative organisations, not only in the development of policy but in the monitoring of states obligations to the Convention. Engagement with people with disability is central to capacity building by promoting a greater understanding of the lived experience of disability. Understanding of the lived experience of disability is critical in informing policy developments and law reform and also in monitoring and highlighting human rights abuses. Disability advocacy is therefore a critical implementation and monitoring tool to progress the human rights of people with disability.

Article 31: Research, collaboration and confidentiality

Central to mechanisms that foster capacity building are research, development and ongoing engagement with people with disability and their representative organisations. The CRPD incorporates two core sets of obligations around research, found in the overarching obligations contained in Article 4 – General Obligations and the stand alone Article 31 – Statistics and data collection.

Article 31 Statistics and data collection, provides that states 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. The Article also incorporates the requirement to comply with established safeguards to ensure confidentiality and the respect of privacy of people with disability. These safeguards require compliance with internationally accepted norms that protect human rights and fundamental freedoms and ethical principles in the collections and use of statistics. The Article also requires that information collected should be disaggregated and used to help assess implementation of states obligations, as well as to identify and address barriers faced by people with disability in exercising their rights. States shall assume responsibility for the dissemination of statistics and to ensure their accessibility to person with disability and others.

Article 4: Research and development

Article 4 General Obligations, promotes research and development. Article 4(f) requires states to promote research and development of universally designed goods, services, equipment and facilities, and (g) to undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies.

Article 32: International cooperation

Apart from these overarching provisions, and as noted previously, another new formulation within the CRPD is Article 32, International cooperation. This is the first time international cooperation has appeared as a stand-alone article in an international human rights treaty. It is derived from elements of the 'International Bill of Human Rights' that foster cooperation with the UN and among states, as well as Article 4 and provisions in the Convention of the Rights of the Child regarding international cooperation. This Article captures the important elements of a broad construction of the obligation upon states.

Article 32 emphasises the importance of international cooperation in supporting domestic efforts in the realisation of human rights and obliges states to undertake appropriate and effective measures between and among states in this regard, but also promotes other partnerships with relevant international and regional organisations and civil society, in particular organisations of people with disability. It promotes unilateral and multilateral resource transfer including aid, information, best practice, scientific knowledge, technical assistance and technologies — all of which are pivotal in capacity building.

Social inclusion and disability research

The text of the Convention clearly points to an ongoing role for people with disability in the implementation of the Convention and highlights the need for donor countries to engage and consult with people with disability. It is seen as of fundamental importance to incorporate people with disability in policy, planning and implementation. The provisions have a strong focus on partnership and outline an important role for people with disability in governance. To include advisory and consultative mechanisms to give people with disability a 'voice' in program development and implementation. This ongoing role reinforces the explicit thrust of the Convention — that disability is one element of human diversity and people with disability share the inherent dignity and worth and the equal and inalienable rights as all members of the human family.

The CRPD provides a framework for states to build inclusive communities. At the heart of this process is social policy as a means of establishing inclusive infrastructure and a means of greater social inclusion for people with disability. The goal of social inclusion presents significant challenges for society in terms of policy reform and structural change. Research and development has the potential to inform this reform process and its implementation. This reform process also creates opportunities through new inclusive approaches, technologies and services — disability as innovation.

Any disability research agenda should be responsive to, and reflective of, the issues confronting people living with disability. A central theme of the CRPD is that people with disability should be actively involved in processes around issues relating to people with disability. This is found within the general obligations of states and within substantive articles. People with disability and their representative organisations played a central role in the negotiations of the Convention embracing the slogan of 'nothing about us without us'. This principle resonates within the participatory and emancipatory research paradigm and informs current methodologies and approaches to social research. An important element of this approach is governance, a means by which people with disability have a voice in the research process. It is critical that any research agenda has a structure in place so as to enable people with disability a role in informing the research agenda.

Participatory disability research seeks to actively engage people with disability and people who support them (families, workers and advocates) in research about policy questions and program evaluations. Research practice has demonstrated that this is difficult to do well. Rhetoric used by researchers and research agencies to support the involvement of people with disability in research on policies that affect their lives often differs dramatically from actual practice. Researchers and research agencies often fail to adopt effective government structures and participatory research methodologies, or to truly collaborate with people with disability and give them a voice in research processes.

Past disability research processes privileged participation of officials, practitioners and families, with the effect of framing disability as a medical or individual experience and objectifying people with disability. People with disability are at risk of being objects of research rather than participants in the research process.

Participatory research: Process, partnerships and development

Participatory methodologies prioritise the voice of people with disability. The intention of the approach is to reflect the experience, needs and expectations of people with disability in the design of research, the policy process, outcomes and the service experience. The aim of the method is to empower people through the process of constructing their own knowledge, and in doing so to increase the relevance of the research.

Participatory research has potential to improve policy and practice but it also presents challenges. It takes longer, may require more dense qualitative approaches in addition to traditional data collection methods to obtain sufficient data to satisfy policy processes, and requires a delicate balance between stakeholders. It relies on sound methodology and ethical considerations from the outset of the research. It requires a commitment to the collaborative and participatory nature of the process. Checks are required to ensure that a process intended to be empowering — where people with disability feel that they are valued partners — does not cause distress and that the contribution of people with disability is not stripped of its context in the data analysis.

The participatory process creates a research partnership between researchers and people with disability. Participatory mechanisms can include formal and informal opportunities to participate in contributing to data, governance and the research process. These mechanisms can include project steering committees and advisory groups as part of the governance structure of the project and people with disability in key roles such as individual expert advisors, peer researchers and reviewers to inform data collection and analysis. Such mechanisms ensure that research questions, instruments and methodologies are informed by people with disability and that data collection and analysis prioritises the experience of people with disability.

This approach to disability research is very important within the development context. Research experience has found that strategies for inclusion of people with disability in the economically poor countries of the ‘South’ have been heavily influenced by the practice in the industrialised countries of the ‘North’. Best practice in the ‘North’ is often disastrous when merely transported to other cultures and contexts. Effective policy change strategies need to include an examination of the barriers to participation at the local level through the experience of people with disability and their families. This provides local and culturally relevant insights to barriers and the potential measures for overcoming them.

A participatory approach to research yields a rich understanding of the lived experience of disability and provides policy makers with an invaluable analysis that captures the voice of people with disability. It is through participatory research and collaboration with people with disability that policy makers in the research process have a basis for informed social policy aimed at building inclusive communities. Participatory research methodologies that truly embrace a collaborative approach promote both the spirit of the CRPD and its objectives in ensuring that people with disability are full and equal participating members of our society.

A disability and development research agenda for Asia and the Pacific

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Background

In August 2010, CBM Australia commissioned a team from the University of Sydney and RMIT University to undertake a short-term project to report on research priorities and capacity in disability and development in Asia and the Pacific region. The project was conducted over a five week period using desk-based reviews, followed by semi-structured interviews with key personnel who attended the Australian Disability and Development Consortium (ADDC) Conference on Disability-inclusive Development in Darwin, 14–17 September, 2010. The research round table held at the conference also contributed further to research data, assisting in providing a brief snapshot of research gaps, priorities and capacity across the region. This article brings together the findings from these components including recommendations for consideration in establishing a disability and development research agenda for Asia and the Pacific.

Research framework

The major frameworks in the disability and development fields, including the UN Convention on the Rights of Persons with Disabilities (CRPD), the UN Declaration on the Right to Development and the Biwako Millennium Framework (BMF), informed each component of the research, which was conceptualised broadly to include the processes of inquiry and building knowledge in the field of disability and development. Beyond readily available resources such as those online library data bases and internet-based publications, the team recognised the existence of additional non English-based content and unpublished grey literature that could not be sourced during the limited time available for this short-term research activity.

Findings from the desk-based reviews

From the desk-based review of literature over the last decade, 45 studies were found that could be described as focusing on both disability and development (ideally, on disability-inclusive development). Most were from countries such as India, Vietnam, Cambodia, Thailand and Bangladesh rather than from countries in the Pacific region. Loosely grouped under four headings, these studies addressed: policy and rights; disability and people's environments; services; infrastructure including information.

Asia and the Pacific constitute a large and important region. Asia has some 60 per cent of the world's population and is growing rapidly. There is a vast range of cultures and languages both across the region and within countries. This apparent anomaly — the size and significance of the region and the small amount of publicly available research on disability and development — suggests potential difficulty for any organisations or individuals who want to use disability inclusive development-related research.

From these studies it appeared that few researchers have a sustained focus specifically on disability inclusive development itself. Some researchers have approached the issue of mainstreaming disability in development by researching the inclusion of people with disability in existing programs. Other researchers have focused on disability-specific strategies, either more narrowly on particular disability groups or through broader strategies such as community based research (CBR). There was little evidence of cross-fertilisation between these groups and limited evidence of researchers involving their participants and disabled people's organisations (DPOs) in emancipatory research practice. Many researchers made explicit, or at least implicit, reference to one or more of the international and regional frameworks on disability and/or development. Human rights frameworks, notably CRPD, the Millennium Development Goals (MDGs) and BMF seemed particularly important.

Interviews, meetings and ideas collated from the Research Roundtable

Given that the focus throughout the project was on research gaps, research priorities and capacity building requirements, it was particularly heartening to encounter sustained commitment to the view that research is critically important for disability inclusive development. This emerged from the widespread view that the many different perspectives on the lives of people with disability often come from anecdote, or hearsay or, all too frequently, only from those able to speak out rather than from any systematic and structured approach to understanding the lives of people with disability and their particular environments. This gives rise to an even larger concern: that is, that there is little good information about pressing issues such as the barriers to participation in development. Given the diversity in disability, and the changes in societies that are affecting the lives of people with disability in ways that are poorly understood, this is particularly worrying.

Research priorities

Five recurring issues emerged as critically important in considering research priorities:

- the lived experience of people with disability in all its richness and diversity;

- the exclusion of people with disability from ‘mainstream’ opportunities, facilities and services of the societies in which they live;
- the need to illustrate the diversity of disability including, but not limited to, culture, gender, impairment, ethnicity, age and place of residence;
- the identification of regularly used terms such as disability, inclusion, development and disability inclusive development and clarifying how these are understood in particular cultural and national contexts; and
- the effectiveness of what is being done, whether policy development and implementation, or programs and their operations, or DPO representation and advocacy.

The desk review findings suggest that research into disability inclusive development in Asia and the Pacific region is in its infancy. The difficulty identifying researchers, over and above the problems of finding out about research, are barriers to developing the field. If researchers and supporters of research cannot locate others with similar topical interests and complementary skills, then each are limited to their own personal networks and to developing their own research. In an emerging field the potential for growth is more likely to be maximised if the stakeholders are connected.

Building research capacity in Asia and the Pacific

The following five strategies emerged as the key foundations upon which to build research capacity in disability-inclusive development in Asia and the Pacific region:

- building and maintaining partnerships and relationships that foster, enhance and sustain research implementation and outcomes;
- embedding resources in all program funding for information gathering, evaluation and research activities, as well as documenting and sharing the knowledge gained;
- information sharing; and
- making disability core business in all aspects of development.; and
- asserting and operationalising ‘nothing about us without us’ as the fundamental principle underpinning the research process from beginning to end.

Summary of recommendations

To develop a sustainable participatory disability and development research agenda in Asia and the Pacific region, several recommendations were made. Principles and guidelines for disability inclusive research should be established and an initial research agenda framed, both building on the CRPD, and drawing on the recurring themes identified during this project. Practical ideas for capacity building of DPOs and other research partners should be shared. In every offer of funding the resources required to build research capacity in the relevant country and among relevant partners should be provided, including active opportunities for training and contribution of people with disability.

It is important to ensure information dissemination and sharing of expertise and practice experience in research across the region. Dedicated funding is required from organisations and agencies to develop and maintain a social networking medium on disability inclusive development and research. A possible mechanism would be an interactive website in which information, reports and research, principles and best practices can be shared, deposited and disseminated, and new partnerships formed, by enabling people with disability, DPOs, NGOs, funders, and governments to find partners with similar interests.

The complete version of the research paper ‘Developing a disability and development research agenda for Asia and the Pacific’ can be found at www.addc.org.au

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Disability inclusion practice: Research findings in Australia and thoughts for future research and practice in the Pacific and Asia

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Introduction

While the Convention on the Rights of Persons with Disabilities (CRPD) affirms and enforces notions of inclusion, research from around the world suggests the practice of inclusion lacks clarity and is ambiguous in translation (Clements et al 2008). Recent research conducted in Australia suggests that the practice of inclusion is further complicated by a lack of systematic planning and resourcing of its multiple elements (Jenkin and Wilson 2009). There is a dearth of research and knowledge pertaining to inclusion practice within Pacific and Asian developing country contexts. Understanding the fundamental need to address more effective inclusive practice within development, this paper explores how broadly defined inclusion work is practiced in parts of Australia. While the Australian milieu is different to developing country contexts, the research findings offer ways to think about and plan inclusion work that serve as useful prompts for discussion.

The research project

The research project *Inclusion: making it happen. Key elements for disability organisations to facilitate inclusion* (Jenkin and Wilson 2009) was conducted in partnership between Deakin University and Scope (a disability organisation based in Victoria). It reviewed the role of disability organisations in working together with people with disability, families and communities to foster inclusion and investigate how disability organisations can enhance their facilitation of inclusion (Jenkin and Wilson 2009). The project specifically aimed to provide clear definitions and examples of what is meant by terms associated with this work such as 'inclusion' and 'participation'. It identified the key factors, enablers, barriers and outcomes that occur at individual, family, community and organisational level associated with inclusion practice. Finally, key organisational tasks or ingredients required to enhance this work were also identified. The focus of the study was not on *why* to foster the work of inclusion, but rather on *how* this can happen, *how* it currently works, *where* the evidence is found of *how* it works, and *how* it is incorporated into identified practices.

Methodology

The research included a literature review from the fields of disability and community development, as well as grey or organisational literature within participating disability organisations; and analysing evidence from interviews conducted with inclusion workers. Interviews were conducted with 17 key informants currently involved in inclusion work from within a variety of service types. For example, day or residential services, community development activity, specialist services work. Two broad sets of interviewees were identified:

- practitioners within Scope, generally seen to have successful experiences in relation to the work of community inclusion. Scope was seen to have a history of inclusion work including a dedicated 'Community Inclusion' section, as well as two work areas actively utilising conceptual inclusion frameworks as practice guides;
- practitioners and program managers across government and non-government organisations in Western Australia. Western Australia was selected due to its extended experience with the local area coordination inclusion model, a different model to that used in Victoria.

Study limitations

As this was as a small study it did not gather evidence of all models of practice and was also limited to the perspective of staff and managers in disability organisations and government. It lacked the scope and timeframe to directly engage with the views and experiences of people with disability which is a significant limitation. The research team recommended a second stage to validate or develop new findings from people with disability as to how disability organisations work alongside them to facilitate inclusion. It would be equally useful to engage directly with the community sector for their views on the inclusion process.

Understanding inclusion

Literature on inclusion is broad and extensive, encompassing a number of key understandings. 'Inclusion' can be understood as a concept embracing a range of understandings, or it can be partnered with other concepts such as 'social inclusion' or 'community inclusion' to highlight a particular set of concepts and values. A range of authors have identified key differences between understandings of inclusion as 'access' (particularly physical access) and as 'presence', contrasted with understandings that add further dimensions of active participation, meaningful social relationships, and active engagement in all life domains (Bigby et al 2009, O'Brien 1987, Wilson 2006). All these ideas are encompassed in the CRPD.

Notions of inclusion often draw on understandings of exclusion and the need to address barriers to inclusion. These barriers are understood in a range of ways. Identifying factors that perpetuate exclusion are akin to the social model of disability that emphasises the way external factors function to create disability. In this analysis, disabling barriers may be physical (physically inaccessible places and spaces), attitudinal, behavioural and structural (including how policies are made and resources allocated).

Inclusion work is sometimes described as creating enabling rather than disabling environments, with a focus on overcoming a wide range of barriers (Swain et al 2004).

These concepts resonate with Sen's ideas connected to freedom (1999). Sen poses the concept of development in terms of 'freedom to' a number of broad life factors and 'protection of' these essential freedoms. He states that for an individual and a society to develop individuals must have tangible and non-tangible freedoms available for them to enjoy. Applying such concepts to definitions of inclusion suggests all human beings would like to participate in priorities that they choose and consider will support their personal development. These freedoms must be available and protected so that the person is not deprived or excluded. Freedoms must not just apply to specified or elite groups but to all members of a society (Sen 1999).

Consistent with Sen and the CRPD, an approach to defining inclusion work for people with disability focuses on the priorities of an individual's life in terms of the whole of who they are and how they live. This broad, whole of life approach emphasises the importance of what an individual wants to achieve, do and be in life. Individuals will choose communities in which they wish to belong, contribute and be valued, and the extent of their presence and participation in these communities. Their involvement is enabled by overcoming barriers that currently function to exclude or devalue them. Inclusion is a broad concept and will therefore mean different things to each person. As facilitators of the inclusion process, 'inclusion work involves supporting people to achieve, do and be in life in the ways they choose and identifying and removing barriers to this in society, services and individuals' (Jenkin and Wilson 2009).

Analysis

Three main approaches in inclusion practice were identified, termed 'orientations' as a helpful way to understand the 'what' of inclusion practice.

Orientation 1: Individual person-centred work leads to inclusion

Inclusion work and community building happen in direct response to expressed interests, needs, and aspirations of specific people with disability.

Orientation 2: Opportunities are created in community

Inclusion work and community building require inclusion workers to be proactive in identifying, creating and offering opportunities to people with disability. This has often been required when people with disabilities live in oppressed environments with limited life experiences and their ability to express interests and aspirations is extremely limited due to lack of opportunity, choice and control.

Orientation 3: Broad level community change

Inclusion and community building focus on broader structural and attitudinal work. This includes work to develop or reframe policies and legislation to support or enable the inclusion of people with disability, as well as work to gain resources or significant infrastructure change (such as accessible public transport). While this work is most powerful when it includes, or is led by people with disability, it does not always include people with disability as actors. This work is generally ground-breaking and foundation-laying with organisations and communities.

The research suggests that inclusion is a broad-scale activity requiring the combined focus of Orientations 1, 2 and 3 in order to ensure that barriers to inclusion are removed at all levels.

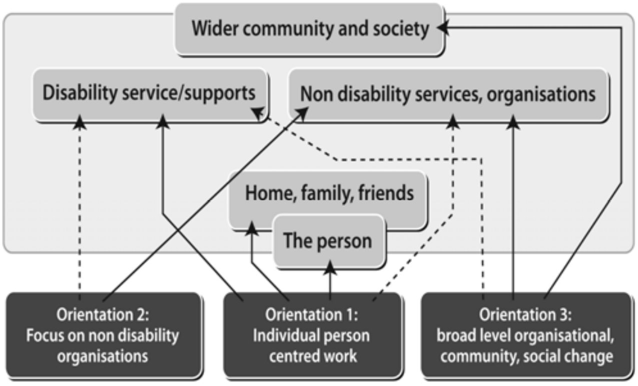

Diagram 1: The focus of the three orientations of inclusion work

Current inclusion work: Implications for change

All respondents identified successful examples of inclusion work, many of which demonstrated the complexity and longevity of the work required. Key changes were identified for organisations and governments to effectively progress inclusion work, drawing together data from respondents about barriers and enablers to inclusion work, and key organisational factors to sustain it. The implications for government, organisations and practitioners to effectively carry out inclusion work follow.

Implications for government

- *Identify current resources, areas of practice and gaps by mapping current investment committed to each of the three orientations of inclusion work.*

Inclusion work is critical to achieving outcomes from all government investment in disability, requiring resources committed to all three orientations of inclusion work and a focus on this work. The concept of three orientations provides a mechanism to systematically review and map current investment, practice and gaps in both government and non-government inclusion work.

- *Inclusion requires identified investment that is long term and based on identified aspirations and areas of need.*

Government needs to lead the change process based on strategic work to overcome existing barriers to inclusion in 'mainstream' communities and disability services. Through person-centred planning and similar approaches, government has a mechanism to identify inclusion priorities that are important to people with disability and to align inclusion work by region, area of interest, or industry, offering new opportunities to invest in inclusion work across all orientations that match collective priorities of people with disability. Directly addressing the barriers to inclusion in this strategic manner requires targeted resources (human, physical and financial) committed for longer-term work rather than one-off, short-term projects.

- *Clarify the practice of inclusion work*

Disability and community organisations are left to interpret 'inclusion' and 'participation' how they wish. Clear guidelines on definitions, as well as breadth of the work, will support clarity and greater consistency in the practice. Explicit government strategies are required to assist organisations with good practice and to promote the importance of inclusion in the community sector. Inclusion work requires clearer accountability mechanisms to ensure all parties accurately evaluate and report on outcomes and barriers to outcomes of inclusion investment. Such accountability mechanisms need to affirm creative and varied approaches to inclusion practice and value outcomes beyond 'presence' by supporting longer timeframes.

- *Actively develop cross-sector collaboration in inclusion work.*

Interdepartmental government approaches are required with cross sectoral collaboration by agencies receiving funding. As an inclusion leader, government needs to resource avenues for people with disability, their families and community organisations to share examples of good practice. This exchange of ideas would generate practical suggestions for improved practice and build motivation, skill development and collaboration.

Implications for organisations

The research findings, based on the experiences of successful inclusion practitioners, provide repeated evidence that inclusion work works. They forms a basis for influencing change and promoting good and consistent practice, resulting in positive outcomes for more people, families and communities. Systematic good practice and organisational support is essential to ensure that *all* people with disability and their communities receive consistent support to be included and inclusive.

- *Inclusion work is core business for disability agencies and must be explicitly present in organisational missions, strategies, staffing and resourcing.*

Inclusion doesn't work unless part of an organisation's task. Prioritising inclusion work has implications for services, organisational strategies and roles and needs to be built into the fabric of an organisation from its mission, strategic plan and organisational roles. Ensure management comprehends, practises and promotes community development principles. Strategically place inclusion workers across the three orientations and ensure regular interface occurs as a priority. Such restructuring is essential if inclusion work is going to be seriously considered and implemented as core business. Without it, other service priorities and deliverables of person-centred approaches, individualised services, and quality practice will be unachievable as people with disability, families and carers remain unsupported in their fundamental aspirations. All planning and action needs to enable long term activity of three years or more that is central to real and sustainable inclusion outcomes.

- *Resource all staff to undertake inclusion work*

Inclusion work needs to be the job of all staff as it requires consistent activity towards identified goals of people with disability. Significant skills development is required for staff to achieve this, along with targeted recruitment strategies that value staff attitudes and values equally with inclusion skills. Professional development programs need to include community development training as a core base to build staff capacity. Staff require skilled supervision and management processes that affirm and support inclusion work. Specialist staff with advanced skills in inclusion work are needed to mentor and support the work as well as leading larger and more complex activities across the three orientations. Organisations need to ensure they resource and value staff who enact practices identified below.

- *Develop organisational systems and processes that are designed to be responsive to individual contexts.*

Highly responsive and flexible systems are needed for individual contexts and aspirations of people with disability. This includes flexible staffing hours, flexible payment and invoicing mechanisms among other systems changes.

- *Identify explicit leadership and collaborative roles for people with disability and their families*

Regardless of the organisation's primary orientation to inclusion work, people with disability and their families must be consulted and supported to drive the work wherever possible. Leadership opportunities for people with disability and families must be opened up in all forms of inclusion work. This process will also support the work to be relevant and sustainable.

Implications for practitioners

The work of inclusion is exciting but often complex. Practitioners need to constantly build their skills in this field.

- *Reflection on practice is critical to successful inclusion work*

Follow and regularly check the work against Ife's (2002) principles of community development to ensure the inclusion work and outcomes are empowering, meaningful and sustainable.

- *Be continually aware of power differences when working with people with disability, their families and communities*

All participants in inclusion work hold skills, knowledge and expertise — to assume an inclusion worker holds more is to reinforce uneven power relations and demean people, families and communities. People with disability and their families are experts in their own lives. Care is required not to assume the worker knows what is best or what the priorities are for an individual or family. Everybody works on different timeframes and within different contexts and pressures. Practitioners need to be flexible and adapt to this and listen to people with disability and their families.

- *Identify and address structural barriers collaboratively*

Be particularly mindful of structural barriers to inclusion that many people with disability encounter on a daily basis. Consciously working to remove these disabling policies, practices, structures and relations creates opportunities for freedom that all people are entitled to. This is likely to require collaboration and alliances with other workers and organisations as structural change requires resources, energy, a wide set of skills and a long time frame. None of this is possible without collaborative work.

- *Allow sufficient time to facilitate inclusion work*

There is no quick fix. Inclusion work is dependent on the quality of relationships that practitioners have built with individuals, families and communities. Trust takes time to develop.

- *Adjust your strategies and approaches based on changing context*

Individuals and communities are dynamic and fluid. Flexibility is required to adapt to changes, catering for the diverse flavours that individuals and local communities bring. What works for one context may be irrelevant for another. Listen to those with whom you work.

Reflecting on inclusion practice within the Pacific and Asia

A range of medical, social or rights-based models of disability can be seen in practice in Asia and the Pacific. Not all endeavour to achieve inclusion (as defined here) as an end result. In some instances, people with disability have led the process and been empowered, where in others, they are viewed purely as recipients of services that are entrenched within a charity model (Macanawai 2009). Given the multifarious models of support in existence, there presents a lack of clarity and consistency around how disability organisations understand and translate the notion of inclusion into action. Less is known about the enablers, challenges and outcomes of inclusion work.

The task of inclusion in the Pacific and Asia is immense. The high mortality rate of children with disability along with extremely low participation levels in education and employment tell us that the rights of people with a disability are far from being realised (Kayess 2009; UN n.d.; Wilkinson 2009). There is no doubt that inclusion work is difficult, nor is there a doubt that it is necessary and called for by people with disability as a pre-requisite for change in their lives. The evidence from this study provides assurance that inclusion work can lead to real and significant change. Our challenge is to better resource, embed and sustain current ad hoc results. For this reason, governments, donors, organisations and people with disability need to be on the same page with systematic, consistent and coordinated approaches if inclusion work is to succeed and be sustainable.

Given our recent insights into inclusion work within Australia, we have ascertained that a range of factors are required to support successful inclusion work. These include clarifying and committing to inclusive practice, embedding inclusive practice into organisational structures, promoting flexibility, working together in partnerships and strategic planning. The need for broader structural enablers (work placed in orientation 3) will further enhance local efforts towards inclusion and open up opportunities for children and adults with disability. Embedding community development principles into inclusion practice will support practitioners to understand their roles, listen to people *with* disability and respectfully work with, rather than for people with disability, their families and communities.

Finally, the call for further understanding from additional research will lead to key recommendations that promote best practice in inclusion work specific to the Pacific and Asian development contexts. The achievement of quality inclusion practice conducted in partnership with people with disability and their families will enhance the capability of the CRPD and contribute towards greater empowerment, opportunities, enriched life experiences and the enjoyment of fundamental human rights for all.

References

Bigby C, C Fyffe and J Mansell 2009, 'From ideology to reality: Current issues in implementation of intellectual disability policy', *Roundtable on Intellectual Disability Policy,* Bundoora, La Trobe University.

Clements T, C Bigby and K Johnson 2008, *Making life good in the community: Building inclusive communities,* Melbourne, Victorian Government, Department of Human Services.

Ife J 2002, *Community development, community-based alternatives in an age of globalisation,* New South Wales, Pearson Education Australia.

Jenkin E and E Wilson 2009, 'Inclusion: Making it Happen, key elements for disability organisations to facilitate inclusion', Melbourne, Scope.

Kayess Rosemary 2009, 'The Convention on the Rights of Persons with Disabilities: Why it is needed', *Development Bulletin,* (73): 13–17.

Macanawai Setareki S 2009, 'Towards inclusive development: Moving forward in addrressing disability in the Pacific', *Development Bulletin,* (73): 36–39.

O'Brien J (ed.) 1987, *A Guide to life-style planning: Using the activities catalogue to integrate services and natural support systems,* in B. Wilcox (ed.) A comprehensive guide to the Activities Catalogue, Pennsylvania, The Maple Press Company.

Sen A 1999, *Development as Freedom,* New York, Alfred A Knopf.

Swain J, S French, L Barnes and C Thomas (eds) 2004, *Disability barriers — enabling environments,* London, Sage Publications.

UN n.d. 'United Nations enable: Factsheet on persons with disabilities ',<http://www.un.org/disabilities/default.asp?id=18>, accessed 3 February 2011.

Wilkinson, Alastair 2009, 'Making disability policy in the Pacific rights-based policy', *Development Bulletin,* (73): 18–21.

Wilson E 2006, 'Defining and measuring the outcomes of inclusive community for people with disability, their families and the communities with whom they engage.'

Research on community based rehabilitation and inclusive development

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Introduction

Community based rehabilitation (CBR) today is understood by most stakeholders in the disability sector as a strategy to promote inclusion, rights and equal opportunities for people with disability. Over the years, CBR practice has changed, from a medical oriented, often single sector approach, to a comprehensive, rights-based approach (Thomas and Thomas, 1999) based on inclusive community development principles.

The term CBR is now well recognised. This recognition of CBR is reflected in the 2004 Joint Position Paper (ILO, UNESCO, WHO 2004) and the newly released WHO CBR Guidelines. Besides, two key articles (Article 26 and Article 19) of the UN Convention on the Rights of Persons with Disabilities (CRPD) make implicit reference to CBR. Article 26 states: 'Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.' Article 19 refers to 'the equal right of all persons with disabilities to live in the community, with choices equal to others'.

The world-wide acceptance of CBR can be seen from a WHO survey (Khasnabis and Heinicke-Motsch, 2008): about 92 countries had CBR projects and programs (35 in Africa, 26 in Asia, 24 in Latin America and seven in Europe). Africa has held three successful CBR conferences, with the fourth being held in Nigeria in 2010. Along with Africa, Asia witnessed the initiation, growth, changes and maturing of CBR over the past two decades. The first Asia Pacific CBR Congress in 2009 that attracted around 700 delegates was the culmination of the combined efforts of stakeholders to consolidate and strengthen what is probably the most significant development over the last 30 years, particularly for those living in rural areas in developing countries.

CBR and community based inclusive development

Community based inclusive development is a term used today for some programs for people with disability and is sometimes taken to mean the same as CBR. Community based inclusive development is an aim or goal to be reached while CBR is the tool or strategy to achieve the goal. Backed by the rationale that no one should be excluded from development for any reason, CBR uses the principles of participatory community development — social justice, self determination, participation, and reflection — in an attempt to make development inclusive of all people with disability. CBR uses a 'twin-track' approach to achieve the goal of community based inclusive development: working with people with disability and disabled people's organisations (DPOs) to build their capacity to become self-advocates for inclusion in all development processes; and working with the community and society at large to remove barriers that exclude people with disability.

Need for research on CBR and inclusive development

Although anecdotal evidence and evaluation reports from different parts of the world indicate the positive benefits of CBR, there is little that is available in the published domain about its effectiveness and impact. CBR programs have been described as 'effective' by Wiley-Exley (2007) in a review of literature. Mannan and Turnbull (2007) have commented that CBR programs have been 'highly effective'. Review studies by Velema et al (2008) and Patel (2007) reported that outcomes of CBR for people with disability included increased independence, enhanced mobility, and greater communication skills; CBR activities were linked to positive social outcomes, enhanced social inclusion and greater adjustment of people with disability. Some researchers (Mannan and Turnbull 2007; Velema et al 2008; Rule and Wolmarans 2006) have reported that CBR has influenced community attitudes positively. De Klerk (2008) has reported that livelihood interventions in CBR resulted in increased income for people with disability and their families, and were linked to increased self-esteem and greater social inclusion. With regard to education, CBR has been found to assist in the adjustment and integration of children and adults with disability (Mannan and Turnbull 2007, Velema et al 2008). There are indications that CBR has been cost effective (Wiley-Exley 2007; Mannan and Turnbull 2007; Patel 2007).

Attempts have been made to review and gather evidence from evaluation reports. Kuipers, Wirz and Hartley (2008) used a systematic, mostly qualitative method of analysis to generate conclusions based on recommendations made in evaluation reports from 37 CBR programs. Velema (2008) reviewed nine evaluation reports of socio-economic rehabilitation projects. Both reviews reported useful evidence on different aspects of CBR.

However, the field of CBR has been criticised for lacking robust research, particularly systematic outcomes research. Kuypers and Hartley (2006), for example, have commented that 'CBR is data rich and evidence poor'. There are increasing calls for a published evidence base for policy and decision making now that CBR is becoming a widely accepted strategy, along with calls for improvement of the rigour, depth, structure and reporting of CBR in research and project evaluations (Finkenflugel, Wolffers, Huijsman 2005), and for more innovative methodologies (Kuipers, Wirz and Hartley 2008).

Some research questions and gaps

The future of CBR lies in more research to address questions related to inclusive development, and the means of promoting it effectively. Some questions on inclusive development for researchers to address at national and international levels are:

- To what extent are people with disability included in Millennium Development Goals (MDG) in different countries?
- What are the key factors influencing implementation of CRPD in different countries? How effective are DPOs in this process? What is the level of awareness and engagement on CRPD among mainstream development agencies?
- What role do DPOs play in mainstream development debate and implementation?
- How can primary health care systems in developing countries (especially remote rural areas) become more responsive to needs of people with disability?
- To what extent is there access to universal design?
- What is the status of implementation of existing disability specific legislation; and awareness of such legislation among primary stakeholders?
- To what extent do mainstream development agencies include disability issues? Are there stated policies? If so to what extent are they implemented? Are people with disability part of the organisations at different levels?
- How can key stakeholders (government, DPOs, other civil society groups) work together to ensure inclusion of disability into all development processes (including conflict and climate change issues)?
- What are the gaps in existing data on disability and inclusive development?
- What are the barriers to inclusion of marginalised groups within the disability sector — due to ethnicity, gender, sexuality, location (unreached communities), category of impairment?
- Can ‘grey’ literature (unpublished reports) be converted to published evidence? For example, a project to write and publish peer-reviewed articles on the effectiveness of CBR, currently only available in unpublished reports.

Gaps

At the moment there are not many opportunities for publishing articles on CBR and inclusive development. Journals that are available and widely read are subscription based and expensive to many readers and CBR practitioners from developing countries. If there are open access journals, authors have to pay fairly high author fees, again making it difficult for most authors from low and middle-income countries.

Given the increasing importance given to general (not specifically medical) disability issues, in particular rights-based approaches, CBR and inclusive development, and the fact that the majority of people with disability live in low and middle-income countries, there is a need for avenues of publication of high international scientific quality, that are freely, openly and universally accessible through different media, including electronic media. In addition, there is a need for high quality, practical information for practitioners and service providers.

Another gap is the absence of research and writing capacity among CBR practitioners and personnel working at the field level in the Asia–Pacific region. There is a great need to build research/writing capacity in this region, to generate more published evidence on CBR.

Funding for research on CBR and inclusive development continues to be a major gap. It is important for the donor community to realise that in order to produce evidence, funds must be available for research on disability and development, which should be apart from/ in addition to, funds allocated for program implementation.

Conclusion

CBR is becoming a world-wide accepted strategy with a conceptual base as reflected in the new CBR Guidelines of WHO. The new understanding of CBR as the strategy to reach the goal of inclusive development is in line with key international frameworks like the CRPD. The time is right to institute rigorous assessment of CBR effectiveness and impact, so that the evidence can contribute to policy making nationally and internationally.

As stated in the 2004 joint position paper of ILO, UNESCO and WHO, ‘CBR is implemented through the combined efforts of people with disabilities themselves, their families, organisations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services’. Inclusive development in the CBR context means that partnerships and alliances are necessary between different stakeholders. Strong partnerships are necessary, especially with DPOs, families of people with disability and with governments in the interest of sustainability.

Because of its multi-dimensional nature, CBR needs networking and building of partnerships at different levels and across different sectors. The goal of community based inclusive development cannot be reached if there is ‘territorialism’ or dogmatic, ‘either-or’ stances on the part of key stakeholders. Instead of territorialism, all stakeholders need to understand the importance of working together to capitalise on each other’s strengths and work in a complementary manner to fulfil the goals and principles of community based inclusive development through CBR.

Research will help to direct future policy and planning on CBR, especially the need to emphasise the connections between CBR and inclusive development.

References

de Klerk, T 2008, ‘Funding for self-employment of people with disabilities. Grants, loans, revolving funds or linkage with microfinance programs’, *Lepr Review*, 79(1): 92–109.

Finkenflugel H, I Wolffers, R Huijsman 2005, ‘The evidence base for community-based rehabilitation: a literature review’, *International Journal of Rehabitation Research*, 28: 187–201.

ILO, UNESCO, WHO 2004, CBR: a strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities. Joint Position Paper, Geneva.

Khasnabis C K Heinicke-Motsch 2008, ‘The Participatory Development of International Guidelines for CBR’, *Lepr Rev*, 79: 17–29.

Kuipers P, S Hartley 2006, 'A process for the systematic review of community-based rehabilitation evaluation reports: formulating evidence for policy and practice', *Int J Rehabil Res*,29(1): 27–30.

Kuipers P, S Wirz, S Hartley 2008, 'Systematic synthesis of community-based rehabilitation (CBR) project evaluation reports for evidence-based policy: a proof-of-concept study', *BMC Int Health Hum Rights*, 8: 3.

Mannan, H and A Turnbull 2007, 'A review of community based rehabilitation evaluations: Quality of life as an outcome measure for future evaluations', *Asia Pacific Disab Rehab Journal*, 18(1): 29–45.

Patel, V 2007, Mental health in low- and middle-income countries, *Br Med Bull*, 81–82: 81–96.

Rule, S L, M Wolmarans 2006, 'Community-based Rehabilitation: new challenges, in Disability and social change: a South African agenda', in B S, Watermeyer, L, T Lorenzo, M Schneider, M Priestly, (eds), Human Sciences Research Council: Cape Town. South Africa, 273–290.

Thomas, M and M J Thomas 1999, 'A discussion on the shifts and changes in community based rehabilitation in the last decade', *Neurorehabilitation and neural repair,* 13(3): 185–189.

Velema, J P 2008, 'Best practices in the socio-economic rehabilitation of persons affected by leprosy and other marginalised people in their communities: findings from nine evaluations in Bangladesh, India and Africa', *Asia Pacific Disab Rehab Journal* 19(1): 3–18.

Velema, J P, B Ebenso and P L Fuzikawa 2008, 'Evidence for the effectiveness of rehabilitation-in-the-community programs', *Lepr Rev,* 79(1): 65–82.

United Nations 2006, *Convention on the Rights of Persons with Disabilities and Optional Protocol*, http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf.

Wiley-Exley, E 2007, 'Evaluations of community mental health care in low- and middle-income countries: a 10-year review of the literature', *Soc Sci Med*, 64(6): 1231–41.

WHO 2010, *Community Based Rehabilitation Guidelines*, Geneva: World Health Organization.

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Inclusive education in South East Asia: Critical challenges in Vietnam, Lao PDR, Cambodia and Indonesia

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Introduction

The slow progress towards meeting Education for All (EFA) targets by 2015 has led to a clearer identification of the barriers to accessing basic education for disadvantaged groups (UNESCO 2010). Croft has argued that the United Nations Millennium Development Goals (MDGs) will not be achieved 'without the inclusion of children with disabilities and young people in education' (Croft 2010:1), disability was not mentioned (Albert, Dube et al 2005), yet significant numbers of children with disability do not have the opportunity to attend school on a regular basis. Some never enter school; others start but make poor progress and drop out (Croft 2010). There is a growing understanding of the link between poverty and disability (DFID 2000).

> Being poor also increases one's probability of becoming impaired and then disabled. This is not surprising as people living in poverty have limited access to basic health care, have insufficient and/or unhealthy food, poor sanitation facilities, and an increased risk and likelihood of living and working in hazardous conditions (Singal 2007:1).

The three projects described have the common aim of working closely with schools and communities in order to improve access and quality for all children, in particular those with a disability and from poor backgrounds. We define inclusive education in its broadest sense and present a brief overview of inclusive and quality education before examining the project work undertaken. We identify a number of critical issues to be addressed through a more systematic approach requiring greater investment in local communities and schools.

Inclusive education and quality education

The meaning of the term inclusive education has changed over the years reflecting the way in which inclusion has become a subject of debate (Peters 2003). For some, inclusion is viewed as an attempt to move away from segregated provision for students with disability towards mainstream placement (Rieser and Mason 1992). For others it is a broader concept concerned with identifying and removing barriers to participation and achievement for all students (Booth and Ainscow 2002), therefore maximising the participation of all in mainstream schools (Allan 2003) and demanding radical changes within schools (Barton 1997). The projects discussed are of the view that inclusive education means an educational approach in which school, communities, parents and children cooperate to remove barriers to participation, enjoyment and achievement at school.

The term quality is often rather loosely defined, often driven by the values and beliefs underpinning education. The Salamanca Statement (UNESCO 1994) emphasises the importance of equality, rights and the contribution of inclusive practices to 'combating discriminatory attitudes, creating welcoming communities … (and) … building an inclusive society'(UNESCO 1994:6). On the other hand, it has been argued that 'an *economist* view of education uses quantitative measurable outputs as a measure of quality, for example enrolment ratios and retention rates ... and cognitive achievement as measured in national or international tests.' (Barrett, Chawla-Duggan et al 2006:2). We argue that this approach has become overriding within a policy setting effectively dominated by Education for All (UNESCO 2008) and the EFA fast track initiative (Buse 2005; World Bank 2008). The measurement of the quality of educational outcomes for children attending schools can be viewed in this way, however, we argue that this approach can also create a smoke screen covering the true story lying beneath the statistics.

Country contexts

Vietnam

Recent Vietnamese history is scarred by war against France and the United States of America, but since *Doi Moi*, or economic reforms of 1986, the country has achieved high rates of economic growth (MoLISA 2008). By 1995, there were resources to invest in social policies such as the achievement of education for all.

Vietnamese policy statements indicate the will to achieve the MDGs (Socialist Republic Vietnam 2005). Five goals have already been achieved with the rest likely to follow by 2015 (Bartholomew 2009). With a primary school enrolment of 95.4 per cent in 2005-2006, it is likely that universal primary education will be achieved by 2015 (MoLISA 2008). Although net enrolment rates are already high, there is still a difficult five per cent to reach, including children with disability, children from ethnic minority groups, those living in remote areas and those coming from poor families (Socialist Republic Vietnam 2005).

The introduction of child-friendly school approaches and inclusive education have often been suggested as a way towards education for all in Vietnam. Signing the UN Convention on the Rights of Persons with Disabilities and the Biwako Millennium Framework of Action have further motivated the development of a comprehensive law on people with disability (Socialistic Republic of Vietnam, 2010). The law stipulates inclusive education should be the main approach of education for children with disability but special and integrated education will continue to exist. In its definition of inclusive education as specified in the Vietnamese disability law (Socialistic Republic of Vietnam 2010) the Government focuses only on children with disability and not on other groups that may be at risk of exclusion from education. Efforts have so far been concentrated on providing access to education and less on quality.

This paper draws upon the reflections, observations and experiences of project partners in Bac Kan, a remote province in the northern highlands of Vietnam, about 160 km from Hanoi. It has a population of some 308,000 and is the third poorest province of Vietnam, with 69 per cent of the population living beneath the poverty line (Socialist Republic of Vietnam 2006). The largest ethnic minority groups are the Tay, Nung, Dao and H'Mong, together comprising 80 per cent of the population.

The Bac Kan Department of Education and Training, Handicap International and Save the Children are cooperating to implement the inclusive education directions of the Ministry of Education and Training. The inclusive education project is supported by AFD (*Agence Francaise de Developpement*) and the European Union (European Institute of Democracy and Human Rights). The main project activities are identification of children with special educational needs, capacity building of teachers and school managers through training and in-school support, provision of resources, awareness raising among community members and local authorities on the importance of education for all, stimulating community involvement in improving the quality of education and the participation of children with disability in community life.

Cambodia

Decades of conflict and political instability in Cambodia have left high numbers of people with disability and an education system on the point of complete collapse (Kalyanpur 2007; Zook 2010). In 1993, the first democratic and multi-party elections were held, allowing Cambodia to engage with the international community. Although many challenges remain, recent data from the Cambodian Government (Royal Government of Cambodia 2006) suggest economic growth and a fall in poverty rates in the early nineties. It is difficult to find reliable school-based data and data about children with disabilities (Zook 2007; Heng et al 2010), with different sources giving different numbers. Data from the UNDP (2010) show a relatively high number of children enrolled in education (89.8 per cent in 2007), but many drop out. Only 54.4 per cent of enrolled children reached the last grade in 2007. Children with disability are least likely to go to school and tend to drop out early (Kalyanpur 2007).

The Ministry of Education, Youth and Sports showed its commitment to reaching the MDGs and the Education for All through a number of policies such as the Cambodian Law on Education for All, the Child Friendly School Policy and the Policy on Education of Children with Disabilities (Hang et al 2010).

The Handicap International project is centred on Battambang, the second largest city in Cambodia. The project aims to enforce Cambodian policies on education for children with disability by strengthening local capacity and their inclusion in mainstream education. The main partners of the project are the provincial and district Offices of Education, Social Affairs and Health. At the community level the project cooperates with the self advocacy group of people with disability of the Chrey commune. The main project activities are capacity building of school staff in providing quality education for all, capacity building in inclusive education management for local authorities and for capacity building in community-based support for community partners. In addition, the project aims to identify children with disability and raise awareness about education for all among the community and local authorities.

Lao PDR

As in Vietnam and Cambodia, Laos has emerged from a period of instability. This is reflected in the progress being made towards meeting the MDGs (UNDP 2010). According to the UNDP Human Development Index, in 1993, Lao PDR was ranked 141st out of 173 countries but had climbed to 133rd by 2009. 'While Lao PDR has made improvements in several areas and is on track to achieve some MDGs, there is concern about the sustainability of MDG gains given the country's reliance on ODA.' (UNDP 2010:1)

Government policy aims to graduate from Least Developed Country status by 2020, requiring sustained and inclusive economic growth. The 7th National Socio-Economic Plan prioritised the MDGs requiring the government to implement a number of key interventions in basic education, health care, agriculture and rural and infrastructure development. Lao PDR signed the UN Convention on the Rights of Persons with Disabilities (UN 2007) in January 2008 and ratified it in September 2009. In 2009, work began between the Government and a range of stakeholders, including NGOs, development agencies and representatives of different groups and communities, to develop a new inclusive education policy. Initial drafts stated that the aim for children with disability was 'to provide learning opportunity for all children appropriate to their individual abilities' through 'provision in the education system for all children with special needs' (CE 2009). It aims to ensure that every school is 'child-friendly' (CRIN 2010).

A small proportion of children in Lao PRD attend pre-school and a similar number go on to secondary school. The teaching language medium is the Lao language, but many children are from ethnic backgrounds with a different first language, increasing potential for language- and understanding-based barriers to participation and achievement in school. Consequently, nationally, these children are less likely to attend school, and when they do, are more likely to drop out (SCN 2008). There are similar challenges for children with disability and those from economically deprived families.

There are approximately 40,000 teachers, many of whom have received only one year of basic training, although the current national strategy is to 'upgrade' teachers both through in-service training and improved initial training. The Ministry of Education in Lao PDR is publically committed to reaching its Education for All targets

(UNESCO 2008) although it has acknowledged that there are serious challenges to achieving these by 2015 (Ministry of Education 2008).

This paper will focus on data collected through the country's 16 year Inclusive Education (IE) Project which ran from 1993–2009 making it one of the longest-running projects of its kind. The IE project aimed to support the participation of all children in school, with a particular focus on disabled students. The main strategy to enable this involved working to change the education system through the introduction of child-centred approaches to teaching and learning in 539 schools across the country. From its inception, the aim of the IE project had been to ensure that students with disability didn't only have access to school but that they also experienced 'meaningful, relevant and quality learning' (Holdsworth 2003:3). There was an acknowledgement that in order to enable children with disability to access school the system would need reform. Existing practice was based on high levels of rote learning and copying from the blackboard, with most teachers having received no professional training.

The project focused on:

- a range of different activities to take place during the lesson;
- increased use of resources;
- a range of approaches to student groupings;
- different questioning styles; and
- the development of lessons which had relevance to real life or learner's own experiences.

During 2008–09, a detailed evaluation of the impact of the project was undertaken by the Ministry of Education together with Save the Children Norway. A detailed overview of the methodology and the findings are described in detail in a recent publication (Grimes 2009). Much of the data we presented here draws on this publication as well as other recent conference papers (Grimes, Sayarath et al 2009; Grimes 2010).

Critical Issues

Through the data collected in all three IE Projects, we can begin to identify a number of themes emerging which have significance for the achievement of the MDGs in Southeast Asian countries.

1. Policy development

In all three countries the projects experienced difficulty translating national policy into practice. This reflects lessons learned internationally (Booth and Ainscow 2002; Booth and Dyssegaard 2009) which indicate that in order to achieve this with 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 the case of 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. Recent research in this field indicates that it is useful to try and clearly identify interlinking cultural factors and constraints and possible facilitators affecting teacher development and the way in which policy can be implemented in schools (Stephens 2007:203–12; Howes, Grimes et al 2009).

In Lao PDR, factors which can be identified as constraining the development of reflective practitioners, which is a pre-requisite for the professional development of teachers, included political, social and religious factors. For example, Buddhism encourages believers to attain a state of no self, where the issues of daily life are irrelevant to the spiritual development of the individual. This may conflict with the development of a professional dialogue which aims to encourage awareness of the 'self' in a school and social context. Additionally, Lao PDR and Vietnam have social structures headed by a one party government which is essentially centralist, authoritarian and hierarchical. This reflects both communist political ideology and deep rooted Confucian influences on Lao society (Stuart-Fox 1997) leading not only to deference to authority but to also any forms of 'support' being interpreted as a covert form of monitoring and control.

Nguyen et al (2009) explore this in some detail in their discussion of co-operative learning in Asia. They identify the importance of conceptualising trust and identity in trying to make sense of the way in which individuals in Asian contexts engage with new developments and initiatives. Experience in Vietnam has shown that it takes a long time to build relationships based on reciprocal trust, although they are pre-requisite to the support of officials at all levels.

Handicap International in Vietnam for example, set up its inclusive education project on a rights-based perspective with a social model of disability. As a consequence, the team believed it would be inappropriate to give gifts to children with disability on special occasions, as this would further stigmatise them as a special group needing special attention. Instead, they supported the inclusion of children with disability and disadvantaged children in existing social events and providing small gifts to all children. Later, it became clear that this way of thinking was quite opposite to the local 'gift culture' and the way relations are normally consolidated. The reaction from some local officers to this was quite negative and made the implementation of further activities more difficult.

The same cultural perspective can be found in all three countries when it comes to implementation and education policies. Although general laws and policies are constructed from a rights-based perspective, implementation strategies often reflect a medical model. In Vietnam for example, implementation strategies focus on financial support, education credit and the creation of favourable conditions for children with special needs rather than on equal rights (Nguyen and Nguyen 2006). Nguyen and Nguyen (2006) describe for example the case of a group of students with a visual impairment who wanted to enter university. The university agreed to give them exemption from the entry exams, but the students felt stigmatised, believing they had the right to take the entry exams like any others in order to prove they had the same capacities. The students believed they had the right to take the exams in Braille.

A further complication in all three countries in the transfer from policy to practice is that the policies remain vague about the choice for inclusive or special education. In Vietnam, the Ministry of Labour Invalids and Social Affairs promotes special institutions, while the Ministry of Education and Training stimulates inclusive education (Le 2000). This is confusing for government staff at provincial and district levels, who have to implement both. In Cambodia, Heng et al (2010) show that in Cambodia there is also confusion and an important number of education officials at provincial and district level and school staff are not aware of the policies supporting inclusive education. This was also the case in Laos where the problem was compounded by the fact that the Ministry of Health retains overall control over the provision for students with disability in special schools even if attitudes have begun to change. One community leader in Luang Prabang province commented that the IE Project had had a significant effect on his village, helping people to work more closely together to positively support those who needed help to overcome barriers to participation in social institutions such as school.

2. Teacher training

The projects in all three countries focus on in-service teacher training to improve inclusive practices in schools. Research and experience around the world and within the IE Project found that attitudes of teachers are fundamental in developing innovative and inclusive practices. The experience of the projects is that where teachers engage with the idea of changing lessons so that all children are participating and achieving, then their attitudes begin to change. They enjoy teaching more, they become increasingly motivated, begin to understand *how* children with disability and special needs can be included in ordinary lessons in mainstream schools. Training in inclusive education projects has been important but it is those aspects of training which supported the development of positive teacher attitudes to disability which have been particularly successful. Teachers need to be shown that all children can enjoy and achieve at school.

Perhaps the key word here is *shown*. It is not enough to tell teachers ‘how’ to change their practice. If one thing is clear from the experience of training within the projects it is that it is hard for teachers to make the transfer from what they have learned in trainings to the daily practice of the school. Training is not enough. Teachers need to visit other schools, discuss ideas and lessons with colleagues and then reflect on how they can try new approaches in their own classrooms. Importing new ideas into schools requires teachers to take ownership of them, adapt them and integrate them into their own practice so that new pedagogies are no longer new but ‘the way we teach in our school’ (Balshaw, Grimes et al 2005).

Strengthening pre-service training for IE is part of the current national strategy in the three countries. In Lao PDR teacher training students follow separate modules on inclusive education based on the UNESCO toolkit on creating inclusive, learning-friendly environments (UNESCO 2004). In Vietnam the universities tend to set up departments on special education with courses on inclusive education. In Cambodia the pre-service teacher training in inclusive education is under development. The existing programs on Lao PDR and Vietnam lack practical knowledge.

Inclusive principles of education need to be embedded in all areas of teaching and learning. There are specific components of core IE training that can be included within an IE module or training course, such as challenging attitudes and misinformation, or approaches to meeting the needs of identified groups of learners such as those with visual and hearing impairments, etc. Inclusive teaching is about:

- providing good quality teaching and learning experiences which engage and motivate children;
- planning lessons that take account of current levels of development and set challenging targets; and
- seeing each child as an individual with individual strengths and needs.

Pre-service training for IE needs to be seen not as an add-on to the existing curriculum but as a way of revitalising and renewing it.

In all the discussions about teacher training, it should not be forgotten that we cannot make the same assumptions about teachers in Southeast Asian countries as in Western countries. In Vietnam, Lao PDR and Cambodia teachers receive a low salary. Many have several other jobs to support their family’s livelihood. When changes take longer to implement or when teachers do not always seem motivated to attend trainings or other activities, project workers and researchers should not make conclusions too quickly.

3. Quality — Access

In all three countries governments have made concerted efforts to improve access to education for all. In the three projects, there is a high enrolment rate in the pilot schools. While it is important to recognise that data collection is challenging in the three countries, as will be described in the following section, overall enrolment rates in primary education are high. The UNDP (2010) identifies in the monitoring of the MDGs the following enrolment rates: Vietnam: 94.5 per cent in 2001, Lao PDR: 82.4 per cent in 2008 and Cambodia: 88 per cent in 2008.

Questions need to be raised about quality of education. Le (2000) argues that in Vietnam children with special educational needs are included in mainstream schools but that almost no additions are made or support given to facilitate the learning and participation of such children. In all three countries children with disability repeat grades often and drop out before completing primary education. In Vietnam, there were instances where children had to repeat Grade 1 up to eight times, finally dropping out at the age at which education is no longer compulsory. The high dropout rates are confirmed through an examination of UNDP figures in the MDG report (2010). Of all the children enrolled in primary schools in Cambodia, only 54.4 per cent reached the last grade. In Lao PDR only 66.8 per cent of the children who are enrolled in the first grade reach the last grade of primary education. Vietnam seems to do better with 92.1 per cent of the children enrolled in grade 1 reaching the last grade. However, it should be noted that the experience of the

Vietnam IE project shows that children with disability are often not included in school-based statistics.

High levels of absenteeism also raise questions about the validity of the high enrolment rates. In the projects in Vietnam and Cambodia we see that children who are coming from poor families or living in remote villages tend to be absent from school, especially during the raining season when roads are less accessible. In the remote areas in Cambodia and Vietnam, schools lack infrastructure to accommodate all children. Children only attend half day schooling in these challenging areas. Often the children from primary school go in the morning to school and the secondary school uses the buildings in the afternoon.

In the Lao PDR IE Project, schools where teachers had received IE training or refresher courses in IE relatively recently were more likely to be aware of developments in child-centred teaching methods, and more likely to be aware of guidance against corporal punishment and the implications of the Convention on the Rights of the Child. The IE 5 Point Star approach (described in above) was used in IE training throughout the Project, but in later years, trainers had improved the model to include more practical detail on ways to make the classroom more child-centred.

This process had been supported by the publication of UNESCO's 'Embracing Diversity Toolkit' (UNESCO 2004, 2009). Although the content of the UNESCO toolkit was not included in the IE training materials, it influenced ways in which IE trainers developed course content. Significantly, the Lao PDR project found that training alone had little impact unless it was supported by a number of other factors:

- School Principals with a good understanding of how to develop inclusive practices to would support all children;
- support from local education advisors who could act as a 'critical friend' (Swaffield 2004) offering both support and challenge;
- a community of practice (Wenger 1998) through local learning networks between schools; and
- close partnership between parents and the community.

4. School based data

There are a number of significant challenges to collecting reliable school-based data about children with disability in Cambodia, Lao PDR and Vietnam. The first is the definition of the terms 'special educational needs', 'disadvantaged children' and 'disabilities' as they do not always fit with the international definitions. In Vietnamese law, disability is defined as:

Persons with disabilities by definition of this Law are those who have impairment of one or more parts of their body, which are shown in different forms of disability, and may cause difficulties in work, daily life and learning (Socialistic Republic of Vietnam, 2010:1)

This doesn't reflect the social model and rights-based perspective as in the CRPD, where disability is defined as:

> Disability is an evolving concept ... (resulting) from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (UN, 2007).

The differences make it difficult to collect and compare data. Experiences from identification activities in the three projects show that the people at the local level who collect data about children do not always have an adequate understanding of what constitutes disability. Further, the concepts of 'disability' and 'disease' are often confused.

The project in Vietnam had made concerted attempts to identify all the children with disability in the project area. It was especially difficult to identify children with more complex disabilities. Due to cultural beliefs parents sometimes feel ashamed of having such children and tend to keep them inside the house. There are also geographical factors creating barriers to collection of data. In the project area there are very remote villages that can only be reached after a long walk through the mountains and across rivers on small mud paths and bamboo bridges. For parents it is very hard to bring children with more complex disabilities to the local health centres or schools for screenings. Despite a significant investment in time and energy, the best estimate the Vietnam project could make amounted to only two per cent of the estimated number of school aged children, still far below WHO estimates which give a benchmark of ten per cent.

To improve knowledge of numbers and location of children with disability, the project started mapping exercises with the local stakeholders. During the discussions to set these up it became clear that some of the data was collected 'from behind the desk' and teachers did not visit the remote places. Although the teachers said all children are enrolled in school, the mapping exercise revealed that this was not the case.

The same could be seen in the Lao project. All school principals and district advisors confirmed that all children living locally were enrolled in school, but this did not correlate with other sources of data. Reports from community health teams and other NGOs, such as Handicap International and Catholic Relief Service who had been conducting small scale house-to-house surveys in villages, indicated that there were significant numbers of students with disability who were 'hidden' statistics — they might not be registered officially with the village committee and not considered eligible to attend school. The Lao IE Projects' conservative estimate was that there were between 40,000–50,000 children with more complex disabilities, who were neither included in official statistics nor attending school.

Conclusions

Comparative research on disability in education in South East Asia is a relatively undeveloped area of academic interest. Perhaps this reflects the way in which academic researchers and development workers have tended to lead separate existences. We hope that in this paper we have been able to break down some of these historical barriers by beginning to explore the findings from development projects in Vietnam, Lao PDR and Cambodia and using these as vehicles to problematise an important area of education. It is significant that the rhetoric from governments often seeks to obscure areas of challenge — pressure from UN development agencies and the World Bank together with significant funding packages tend to encourage an unduly positive outlook. As we write, the draft of the latest UN MDG report is being debated in New York and is already being criticised (OXFAM 2010) for lacking detail and being over optimism.

The research presented here raises many important issues, but in the context of achieving the MDGs, perhaps most sobering is that neither Cambodia, Lao PDR nor Vietnam are able to make a convincing estimate of how many children of school age have one or more disabilities, nor how many are not attending school. Current government estimates in all three countries do not match the experience of the three projects nor relate to World Bank estimates. In the light of this, it seems reasonable to conclude that access to education for children with disability in these countries has a long way to go before we can conclude it is not a significant problem. In regard to the quality of education for children with disability who are in school, it also seems clear that there is much yet to be done if traditional pedagogy is to develop into more child-centred approaches to provide a meaningful and supportive environment for all children.

It is also appropriate to note that there are positive examples of more inclusive practice being developed in all three countries. We acknowledge that change takes time even if the EFA/MDG agenda does not allow for this. In the rush to meet a set of artificial deadlines imposed by the international community it may be that some groups of children will get left behind as governments and development agencies ignore findings such as ours. Sustainable change requires a grassroots, community-based approach, as well as policy development and systems change. This takes time and a channelling of funding into communities and school-based projects. It also requires that more attention be paid to assumptions about the way in which teachers develop their practice and communities change their attitudes.

References

Albert, B and A K Dube, et al 2005, ‘Has Disability Been Mainstreamed into Development Cooperation?’ Disability Knowledge and Research Programme, Norwich/London: Overseas Development Group, University of East Anglia/Healthlink Worldwide.

Allan, J 2003, *Inclusion, Participation and Democracy: What is the purpose?* Dordrecht, The Netherlands, Kluwer Academic Publishers.

Balshaw, M and P Grimes, et al 2005, ‘Effective Schools are Inclusive Schools’, XVIII International Congress on School Effectiveness and Improvement Barcelona, Spain.

Barrett, A M and R Chawla-Duggan, et al 2006, The Concept of Quality in Education: a review of the international literature on the concept of quality in education.

Barton, L 1997, ‘Inclusive Education: Romantic, Subversive or Realistic?’ *International Journal of Inclusive Education,* 1(3).

Booth, T and M Ainscow 2002, *Index for Inclusion: Developing learning and participation in schools,* Bristol, Centre for Studies on Inclusive Education.

Booth, T and B Dyssegaard 2009, *Quality is not Enough: the contribution of inclusive values to the development of Education for All*, DANIDA.

Bunting, I A 1993, ‘Rationalisation, Quality and Efficiency’, *South African Journal of Higher Education* 7(2): 17–27.

Buse, K 2005, *Education for All — Fast Track Initiative: review of the Governance and Management Structures* London, Overseas Development Institute.

CE 2009, *Lao PDR: Sector-Wide Approach in Education Sector Development,* C. Education.

CRIN 2010, *Child Rights References in the Universal Periodic Review: Lao PDR,* Child Rights Information Network.

Croft, A 2010, ‘Including Disabled Children in Learning: Challenges in Developing Countries’, *Consortium for Research on Educational Access, Transitions and Equity: Pathways to access Research Monograph No. 36,* Brighton, University of Sussex Centre for International Education.

DFID 2000, *Disability, poverty and development*, DFID policy document.

Grimes, P 2009, *A Quality Education For All: The History of the Lao PDR Inclusive Education Project 1993–2009,* Vientiane, Save the Children.

Grimes, P 2010, ‘Inclusive education in Lao PDR: learning from local responses’, The 7th Inclusive and Supportive Education Congress, Queen’s University Belfast.

Grimes, P and K Sayarath, et al 2009, ‘The Lao PDR Inclusive Education Project 1993–2009: Reflections on policy evolving into practice’, 10th UKFIET International Conference on Education and Development, Oxford. Oxford, England.

Holdsworth, J 2003, *Seeking A Fine Balance: Lessons from Inclusive Education in Lao PDR,* Vientiane, Save the Children UK.

Holt, M 2000, ‘Introduction: the concept of quality in education’, *Improving Quality in Education,* C Hoy, C Bayne-Jardin and M Wood. London, Falmer.

Howes, A and P Grimes, et al 2009, ‘Imagining inclusive teachers: contesting policy assumptions in relation to the development of inclusive practice in schools’, 10th UKFIET International Conference on Education and Development, Oxford.

Heng, C, K Piseth and N S Kanika, April 2010, ‘Report on Current Situation of Education for Children with Disabilities’, Cambodian Disabled Person’s Organization. Phnom Penh.

Kalyanpur, M December, 2007, *Including the Excluded. Integrating disability into the EFA Fast Track Initiative processes and National Education Plans in Cambodia*, World Vision Cambodia.

LE, V T 2000, ‘Inclusive Education — A New Phase of Education in Vietnam, Including the Disabled, International Special Education Congress, 24–28 July 2000’, University of Manchester.

Ministry of Education, 2008, ‘Education For All Mid Decade Assessment’, Lao PDR**:** 166.

MOLISA 2008, *The 3rd and 4th Country Report on Viet Nam’s Implementation of the United Nations Convention on the Rights of the Child in the 2002–2007 Period,* Hanoi.

Nguyen L and T K H Nguyen, November 2006, *Report on Research on Support Policies for Disadvantaged Students*, http://www.pathwaystohighereducation.org/countries/c.php?id=21, accessed 1 December 2009.

Nguyen, P and J Elliott, et al 2009, ‘Neocolonialism in education: Cooperative Learning in an Asian context’, *Comparative Education* 45(1): 109–130.

OXFAM 2010, ‘Clock is ticking, time to put words into action on the MDGs’, http://www.oxfam.org.uk/applications/blogs/pressoffice/2010/09/10/clock-is-ticking-time-to-put-words-into-action-on-the-mdgs/?v=media, accessed 10 September 2010.

Peters, S 2003, *Inclusive Education: achieving education for all by including those with disabilities and special educational needs*, Geneva, World Bank.

Rieser, R and M Mason 1992, *Disability Equality in the Classroom: A Human Rights Issue,* London, Disability Equality in Education.

Royal Government of Cambodia, Ministry of Planning 2006, *A poverty profile of Cambodia 2004,* Phnom Penh.

Socialistic Republic of Vietnam June 2005, *Education law,* No38/2005/QH11, Hanoi.

Socialistic Republic of Vietnam 2006, *Household Living Standard Survey 2006,* Hanoi.

Socialistic Republic of Vietnam 2010, *The National Law on Persons with Disabilities,* National Assembly, Hanoi.

Sayed, Y 1997, 'The concept of quality in education: a view from South Africa', Educational Dilemmas: debate and diversity, K Watson, C Modgil and S Modgil (eds), *Quality in Education 4*, 21–29, London, Cassell.

SCN 2008, *Save the Children Norway in Lao PDR Diary 2009,* Vientiane, Save the Children Norway in Lao PDR.

Singal, N 2007, 'Conceptualising disability and education in the South: Challenges for research', Research Consortium on Educational Outcomes and Poverty Working Paper, University of Cambridge.

Slee, R 2004, 'Inclusive Education: a framework for school reform', *Inclusive Education: a framework for school reform,* MAV Heung, Hong Kong, Hong Kong Institute of Education.

Stephens, D 2007, *Culture in Education and Development,* Oxford, Symposium Books.

Stuart-Fox, M 1997, *A History of Laos*, Cambridge, UK, Cambridge University Press.

Swaffield, S 2004, 'Exploring Critical Friendship through Leadership for Learning', 17th International Congress for School Improvement and Effectiveness.

UN 2007, *Convention on the Rights of Persons with Disabilities,* New York, UN.

UNDP 2010, *The Millennium Development Goals in Lao PDR,*United Nations Development Programme.

UNESCO 1994, *Salamanca Statement.*

UNESCO 2004, 2009, *Embracing Diversity: Toolkit for Creating Inclusive*, *Learning-Friendly Environments*, Bangkok, UNESCO.

UNESCO 2008, 'Education For All by 2015 Will we make it? Summary', *Global Monitoring report*, Paris, UNESCO**:** 41.

UNESCO 2010, *Education for All Global Monitoring report: Reaching the Marginalized*, Paris Oxford, UNESCO.

Wenger, E 1998, *Communities of Practice: learning, meaning and identity,* Cambridge, Cambridge University Press.

World Bank 2008, The Road to 2015: Reaching the Education Goals Education for All Fast Track Initiative, Washington, DC, World Bank.

Zook, D C 2010, 'Disability and Democracy in Cambodia: an integrative approach to community development building and civic engagement', *Disability and Society,* 25 (2): 149–161.

Notes

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Greater education access for deaf youth: Moving forward with the help of partners

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Introduction

The Centre for Education Access and Development (CEAD) of the De La Salle-College of Saint Benilde (DLS-CSB), is a newly created centre tasked to develop 'new grounds and initiatives that shall benefit deaf people through advocacy, research, training and development, and policy change in one or many areas related to access and equity of education' (*Bridge*, Issue 2). For the last 19 years, DLS-CSB has been involved in the tertiary education of select Filipino deaf youth under the leadership of the School of Deaf Education and Applied Studies (SDEAS), one of six academic schools of DLS-CSB. At present, there are 8000 students in DLS-CSB, 200 of whom are deaf. To date, 249 have graduated and 154 are employed or are in business in one of the following fields: graphic design, computer applications in businesses, service professions in the hotel and restaurant industry, education, counselling, development work, and sports.

De La Salle-College of Saint Benilde is one of the 17 La Salle Schools of the De La Salle Philippines (DLSP) Network. This network is part of a worldwide network of schools founded and managed by the De La Salle Brothers of the Christian Schools that originated in France. Aside from DLS-CSB, two other La Salle schools provide support for the education of deaf children and youth while another is providing assistance to help a struggling self-contained school for the deaf that recently suffered major financial and property loss due to typhoon and flood damage.[2] These schools, like DLS-CSB, provide partial or full scholarships for the poor and marginalised among its deaf students. This kind of access is a mandate of DLSP to make education accessible to the poor, disadvantaged children and youth.

The target outcome of CEAD is not just to make education financially accessible to deaf students but to help its institutional partners develop a more rights-based, inclusive and barrier-free environment and expand career development opportunities of deaf people to improve their life circumstances. To better understand this direction, it is important to understand the history of our growth.

History of DLS-CSB deaf education

According to the Asia Pacific Centre on Disability, there are at least four types of barriers faced by people with disability — structures, information, systems and governance and attitudes (Edmonds, 2005). When DLS-CSB ventured into deaf education, we were unaware of the existence of these barriers and even more unaware of the impact of these barriers on the learning and development of deaf students exposed to them for many years. It was only through direct experience that the educators realised that norms and interventions accepted as standard and effective practices for hearing students were not effective in helping deaf students fully develop their potential and capabilities.

The lack of understanding as well as limited benchmarks on how best to help deaf students was a challenge that emphasised the need to further understand the unique needs of deaf people and appropriate strategies that were different to those we knew. Education in a self-contained set up was deemed the appropriate intervention[3] — to give the administration, faculty, and the students, flexibility to understand the needs we were faced with and hence be more responsive. As a learner-centred institution, it was natural to value the uniqueness of deaf people as legitimate and valid. Despite many aspects that we did not understand, the mission of DLS-CSB helped us since it 'recognises diversity by addressing various needs, interests and cultures … actively anticipate and respond to individual, industry and societal needs by offering innovative and relevant programs that foster holistic human development'.[4]

The goal of the self-contained arrangement was not to isolate deaf students but to prioritise needs of deaf learners. Academic and personal goals for the general population were the same for the deaf population. Our exposure to deaf people, our students and those who advocated for their rights, helped us create and advocate for customised interventions and accommodation that were not the mainstream norm. As a learner-centred institution we understood that equity in education does not mean everyone is treated the same. 'Equity recognises that some people require additional and specialised support to achieve equal benefit' (*Our children, our communities and our future*, 2007).

The role of organisations for and of deaf people

While our development occurred against the backdrop of the United Nations global call for countries to recognise the rights of people with disability,[5] it was our exposure to different organisations for and of deaf people and other educational institutions with deaf programs that helped us in our efforts to be more attentive to the needs of the deaf. The direct and indirect forms of interaction opportunities allowed our team to be more exposed to deaf people's activities, aspirations and directions. We learned to understand and recognise their rights as deaf people, their cultural identity and their natural sign language now known as Filipino sign language as not less but equal to the rest.[6] We also realised that these rights and identity had an influence on experiences, learning styles and self-esteem.

The role of PEN-International

DLS-CSB SDEAS became a partner of the Post-Secondary Education Network-International (PEN-International) in 2002. PEN-International is a global network of universities and colleges with deaf programs established to help improve the circumstances of deaf students in post-secondary education around the world.[7]

PEN-International used the Import-Capability Building for Self Sufficiency-Export as the framework of its assistance model. After helping DLS-CSB SDEAS identify its pressing needs and the direction it wanted to go, PEN-International provided all support needed to bring forth access to information and capability-building opportunities.[8] Through this partnership, SDEAS benefited extensively. The partnership helped us to become more self-sufficient and capable in our responsibilities to provide better education to the deaf students; gave us the confidence to advocate and lobby for change; raised the credibility of SDEAS in the community; and improved our relationships with partners (Dela Torre, De Caro and Clymer, 2005).

Today, SDEAS operates as a self-contained school in DLS-CSB. Thirty-four of its 50 personnel (administrators, faculty, and staff) are deaf people. The rest are hearing signers, some of whom also serve as educational and community interpreters. SDEAS has three dedicated centres for particular needs of deaf students: Academics; Deaf Esteem and Formation; and Partnership and Development. The first two are focused on needs of the students for competence and confidence; the latter focuses on employment needs or business settings by providing advocacy, mentorship and training to hearing people who will work with deaf graduates in various capacities.

In addition, the DLS-CSB administration has grown more accepting of necessary interventions such as:

- policies lobbied for the benefit of the deaf successfully passed, including recognising interpreters as professionals;
- increased scholarship funds;
- increased hiring of deaf people in employment opportunities within the institution; and
- increased participation of deaf people to more student development opportunities over and above what is already provided to them in SDEAS.

There is also an increased sensitivity and recognition of the importance of Filipino Sign Language (FSL) and the deaf identity through increased enrolments in sign language courses. In addition, the institution provided partial and full subsidy to those who may be directly involved in providing support to deaf students through student services and formation activities (Perez, 2010).

Outcomes of partnerships: Barriers and opportunities

The role of partnerships has helped our efforts to be more learner-centred and to be trail blazers and offer alternatives to traditional ways of helping deaf people gain access to education. However, these efforts largely remained within the self-contained setup with some form of inclusion.

Despite the successes of our efforts — in educating in a self-contained setup, providing opportunities for employment and forging partnerships to reinforce acceptance and recognition of the deaf identity within DLS-CSB and among our external partners — convincing other DLS-CSB academic schools to provide access to their programs remained a limitation.

The rest of the DLS-CSB community needed to understand the ‘whats’ and ‘hows’ to make inclusion possible. Unfortunately, necessary information and capacity-building opportunities were not accessible because these were not evident in the environment they were part of; which in turn made it difficult to convince them that there were indeed possibilities to work with and eventually became barriers for others to fully support inclusive efforts. As a result, policies could not be put in place because key decision makers were not convinced of the possibilities of success. As pointed out in the *Manual for Admissions of Persons with Disabilities* the difficulty lies in ‘the lack of information and preparation by school administrators and teachers alike on how to handle students with disabilities …’ (National Council of Disability Affairs (In Press).

Meanwhile, other partner schools that went ahead to provide some form of education access to deaf students through self-contained and mainstreamed arrangements also experienced barriers. They were in need of mentors and assistance to advocate for deaf rights and lobby for more support as a result of the unique needs of their deaf students. While SDEAS provided support through the years, there was still a need to help provide additional assistance for capacity building towards self-sufficiency.

During this time, exposure to national and international development directions toward inclusion of people with disability became evident to SDEAS — through participation in various initiatives involving consultations, conferences, indignation rallies and crisis response initiatives, to name a few.[9]

Education access strategy: Exporting within to achieve self-sufficiency

Upon the request of SDEAS, PEN-International provided support to begin the capacity building of its DLS-CSB administrators to convince them to support the direction towards inclusion. A week’s educational exposure of select DLS-CSB administrators was funded for them to benchmark possibilities with a model institution where both the self-contained set up and inclusive education for the deaf was possible. Prior to the benchmark, the members clarified their expectations and beliefs as an opportunity to check their perceptions and attitudes towards inclusion and deaf people. An ad hoc committee on Education Access for the Deaf (Project AhEAD) was created to monitor and set directions for education access.

AhEAD delegates visited the Rochester Institute of Technology-National Institute for the Deaf (RIT-NTID) in Rochester, New York, and it was there that they witnessed the great possibilities of making DLS-CSB more inclusive for deaf students. A range of opportunities for student services, faculty support, technology use and training that helped make inclusion of deaf students in the Rochester Institute of Technology possible was showcased to the administrators, who interacted with RIT-NTID key leaders, faculty and RIT deaf students. The team came home excited and full of ideas. It was at this point that suggestions for more capacity-building activities towards inclusive education became more attractive to the internal partners. Despite the fact that the transition between self-contained to inclusive education had gray areas to further understand, the DLS-CSB administration were convinced that moving towards this direction was an important stance to reiterate its seriousness to make its education accessible to the deaf and to other people with disability in the future.

Education access through partnerships

In its eighth year of partnership with PEN-International, DLS-CSB created the Centre for Education Access and Development (CEAD). Implementing the PEN-International Import-Capability for Self-Sufficiency-Export model, CEAD serves as a resource and development centre to help partners identify and overcome their barriers to achieve the direction it has set and make education accessible and equitable to deaf people.

Some of the functions of CEAD are:

- to help clarify needs and provide guidance towards the mutually acceptable direction of making the academic environment more rights-based, inclusive and barrier free to deaf people and to ensure that support provided will increase chances of success for the partners;
- to lobby for support, provide capacity-building opportunities and guidance so stakeholders may become self-sufficient exporters of knowledge and competence for others to benefit; and
- to help deaf students have greater access to and equitably learn from the education of their choice.

Training and development for specific purposes are achieved through the assistance of deaf and hearing resource people and advisers in specific fields in deaf Education from the School of Deaf Education and Applied Studies of the De La Salle-College of Saint Benilde, the Rochester Institute of Technology-National Technical Institute for the deaf or from organisations for and of deaf people, and other educational institutions with deaf programs. Grant support for this initiative partially comes from DLS-CSB and to a great extent from PEN-International.

At present, CEAD has two major on-going projects that involve DLS-CSB SDEAS, an academic school and external partner of DLS-CSB, and other partner schools in the DLSP Network.[10]

Project AhEAD

Project AhEAD was designed to assist partners in preparing its courses and faculty to make their education accessible and equitable to deaf students. It also supports the implementation of an evolving educational interpreting program to facilitate the increase in home grown interpreters, who can be tapped for inclusive efforts for the deaf. The initiative is highly developmental and non-prescriptive — working with current needs of the primary partner and creating and co-developing interventions with internal partners. At present, the School of Hotel, Restaurant and Institution Management (SHRIM) is in partnership with CEAD and SDEAS to prepare their faculty, staff and students to be inclusive by June 2012.

Some of the strategies implemented for this preparation are learning the FSL and deaf culture. Short term learning sessions are being conducted to allow teachers to gain guided experiences in teaching the deaf as well as help deaf students learn basic culinary skills. This arrangement is with the mentorship of assigned educational interpreters and mentors. Other workshops have been scheduled to learn specific strategies in teaching the deaf. As an outcome of this partnership, SHRIM has spearheaded in lobbying for more employment opportunities in the hotel industry that facilitated the partnership of DLS-CSB and the Shangri-La Hotel-Makati City and paved the way for the training of deaf graduates for potential employment. As part of our strategies, the Shangri-La hotel partner underwent deaf culture awareness workshops and basic Filipino Sign Language classes. OJT students were also provided support seminars by SHRIM and reflection workshops by SDEAS for self-awareness and deepening.

In succeeding years we envision that the processes we have implemented with SHRIM can be replicated in the Schools of Design and Arts and Management, Information and Technology.

Secondary education initiatives

PEN-International funded a series of consultations with students and faculty from select high schools for the deaf — to generate a profile of current needs and aspirations to make secondary education more accessible and equitable to the deaf. The outcome led to the creation of the Secondary Education Initiatives (SEcI) for select secondary partner schools with deaf programs aimed to enhance their programs and services to become models and serve as benchmarks in deaf education. It is hoped that this will inspire the movement towards further enhancement of deaf Education in the Philippines. Like the college set up, PEN-International provided support to the SEcI network to undergo educational exposure training and learn from faculty, administrators and students of three model schools for the deaf for self-contained, mainstreamed and inclusive programs abroad. Plans are underway for more capacity building projects that are tailored to fit expressed needs and interests.

Conclusion

It is the right of deaf people, and other people with disability to have access to and learn equitably from the education of their choice. However, barriers in society exist that prevent them from this opportunity for their development. As experienced by our community, these barriers are mostly a result of the lack of information and preparation of the decision makers, faculty and staff to respond to the unique needs and context of deaf learners. The absence or lack of information and competence can lower people's confidence to appropriately handle these needs. This is a reality for both educators and advocates of deaf people and any who are asked to handle them in an inclusive environment.

Capacity building of those involved in education of deaf people, deaf or hearing is critical to facilitate greater access and equity of education. As a preliminary component, educators need to be exposed to, understand, recognise and accept the truth that deaf people have equal rights and that their uniqueness, issues, and needs are legitimate and valid. This can be accomplished when educators and advocates interact and work closely with Disabled People's Organisations and people with disability, and they are involved in setting directions, creating opportunities, and implementing interventions.

Another critical component to pave the way for inclusion is through partnerships. Partnerships with agencies and organisations for and of deaf people who are respected and credible in society can help advocates and organisations who are building their capacity to gain the attention and support of the mainstreamed environment because of their association and partnership with them. However, these key partners must be very clear with their role to serve as mentors and support to help younger organisations to evolve. The main strategy should be developmental, not prescriptive.

The road ahead for DLS-CSB is full of promise. We hope to learn as much as we can and to do so in partnership, to set up necessary support and guidance to create the bridges necessary to make our educational opportunities more accessible and equitable to deaf people, and in the long run to other people with disability.

References

Dela Torre, T C, J De Caro, and E W Clymer 2005, 'Higher education for deaf students in the Philippines today: The role of De La Salle-College of Saint Benilde, the deaf community and PEN-International', paper presented at the conference on Higher Education for Students with Disabilities, Waseda University, Tokyo, Japan, March 27, 2005.

Dela Torre, T C 2009, 'Progress report of PEN Philippines', paper presented at the PEN International Forum in Changchun Hotel, Changchun, China, September 11–12, 2009.

National Council on Disability Affairs, Office of the President, Philippines (In Press), *Guidelines in the admission of students with disabilities in higher education and post-secondary education institutions.*

Edmonds, L 2005, *Disabled people and development*, Poverty reduction and social development division regional and sustainable development department Asian Development Bank. <http://www.adb.org/Documents/Reports/Disabled-People-Development/disabled-people.pdf>, accessed online August 7, 2006.

Our children, our communities and our future, equity in education a policy framework, 2007, <http://www.sasked.gov.sk.ca/equity/>, accessed online February, 2009.

Perez, M V T 2010, 'The use of Filipino sign language in providing academic support services to deaf students', paper presented at the 1st Philippine Conference-Workshop on Mother Tongue-based Multilingual Education held at Capitol University, Cagayan de Oro City, Philippines, February 19–20, 2010.

'What is CEAD?' *BRIDGE Building bridges, creating opportunities, improving deaf lives*, Issue 2: SY 2008–2009 and 2009–2010, Centre for partnership and development, school of deaf education and applied studies, De La Salle-College of Saint Benilde, Manila Philippines.

Notes

1 The author is Director of the Centre for Education Access and Development (CEAD). She served as the immediate past Dean of the School of Deaf Education and Applied Studies (SDEAS) 2002-2009, and Director of the School of Special Studies from 2000-2002. Prior to her administrative positions, the author served as guidance counsellor for the deaf from 1991–2000.

2 Adult Night HS of La Salle Greenhills (LSGH-ANHS). The La Salle University-Ozamiz offers two types of programs for students: The School for the Deaf (self-contained elementary and high school) and the mainstreamed program for a select number of deaf students in the Tourism and Hospitality Management School of the university. La Salle Academy-Iligan provides assistance to help a struggling self-contained school for the deaf that recently suffered major financial and property loss due to typhoon and flood damage.

3 Prior to the implementation of the deaf program, DLS-CSB had other self-contained arrangements for other types of students in the college. These were classes for working students and students on academic probations, for example.

4 To learn more about the DLS-CSB Vision Mission please visit <http://www.dls-csb.edu.ph>.

5 UN Decade of Disabled Persons from 1983–1992, Asia and Pacific Decade of Disabled Persons from 1993–2002, and then again from 2003–2012.

6 Other significant partners in early years of the deaf program who provided consultants, trainers, teachers, interpreters and advisers were from the following: Catholic Deaf Care (CDC), Catholic Ministry to Deaf People (CMDP); St. Augustine School for the Deaf (SASD); Philippine Association of the Deaf (PAD); College Assurance Plan School for the Deaf; Internacional Teatro Silencio Filipinas; Deaf Volunteers from Voluntary Service Organisation (VSO). In latter years, other organisations that also provided information or consultants, trainers, interpreters, teachers or became sponsors of various advocacy initiatives: Philippine Federation of the Deaf; Deaf Women's Crisis Centre; Philippine Deaf Resource Centre; Manila Christian Computer Institute for the Deaf.

7 PEN-International is under the leadership of Dr James DeCaro, Director of PEN, who is also the Interim President of the National Technical Institute for the Deaf in Rochester Institute of Technology, Rochester, New York. The goals for PEN-International are to:

- train faculty for improving, teaching and learning;
- apply innovative instructional technologies to the teaching/learning environment;
- provide state-of-the-art equipment to international partners;
- promote program self-sufficiency; and
- expand career opportunities for deaf and hard-of-hearing students.

PEN is funded in full by The Nippon Foundation of Japan. For more information about PEN please visit their website: http://www.pen.ntid.rit.edu

8 Some of the strategies implemented by PEN International involved showing benchmarks, improvement of teaching and learning, use of learning tools, interaction with different role models among deaf students and teachers, sharing of success

stories and possibilities. There were faculty and student exchanges for cultural appreciation and sharing of knowledge. Friendships were developed, teaching opportunities were shared.

[9] SDEAS participated in some of these initiatives which involved consultations, conferences, rallies, mobilisation activities for crisis response. Those that we interacted with constantly were the Philippine Federation of the Deaf, National Council on Disability Affairs, *Kapisanan ng mga May-Kapansanan sa Pilipinas* or KAMPI (a federation of DPOs), Philippine Council for Cheshire Homes for the Disabled, Philippine–Australian Community Assistance Programme (PACAP) and AusAID.

[10] At present, the School of Hotel, Restaurant and Institution Management, one of the five other academic schools in DLS-CSB is preparing for inclusion of deaf people. For other La Salle and partner schools, the following organisations are currently working with DLS-CSB CEAD: La Salle University-Ozamiz (self contained elementary and HS; mainstreamed tertiary); La Salle Greenhills-Adult Night HS (mainstreamed); and the Bible Institute for the Deaf (self-contained elementary and HS).

Partnerships in providing services for the disabled in disaster and emergency situations

Maryanne Diamond, World Blind Union[1]

Over recent years we have heard a great deal about the term 'partnerships' in development and disability. The establishment of the Australian Disability and Development Consortium (ADDC) has provided the opportunity for many of us working in disability and development to come together and is therefore a perfect example of one kind of partnership. I look forward to further progress in years to come.

I want to focus here on what has worked well in this sector and what has contributed to success. It is easier to focus on challenges, but this is not very motivating for people wanting to bring about change.

This paper covers four things:

- the importance of defining and selecting appropriate partners, in this case from the perspective of the World Blind Union (WBU);
- what is meant by partnerships in disaster and emergency situations, using the horrific example of Haiti;
- some examples of good practice that followed the Haiti earthquake; and
- the success factors which make development processes and partnerships truly inclusive of disability issues.

WBU is a global organisation representing the 161 million people who are blind or have severe vision impairment. According to WHO, there are an additional 153 million people who have vision impairments that can be corrected, but due to a range of factors have not. WBU has a number of membership categories, of which the main category is by country. Currently there are 190 countries divided into six regions.

Selecting partners

The history of WBU helps explain its approach to selecting partners. WBU was established in 1984 by the coming together of two international bodies: the World Council for the Welfare of the Blind and the International Federation of the Blind (IFB). One body represented the service providers and the other the blind. Working together provided a greater opportunity to develop and deliver services which met the needs of all.

As part of the merger negotiations, it was laid down in the constitution that all national delegations must have at least 50 per cent of their delegation coming from organisations of the blind. Countries that do not have such organisations cannot be accepted as full members: they are classified as special members and are required to establish an organisation of the blind before they can be considered for full membership.

By defining who we partner with, it is fair to say that in some areas we have been successful in supporting the establishment of organisations of the blind. With support from the Scandinavian countries, Spain, the United Kingdom and Canada to name a few, we have been able to establish very good regional bodies in Africa, South America and Asia. These are slowly building strength, often with the commitment of only a few individuals.

WBU has used partnerships as a way to support our country member organisations. In Africa it runs in partnership with US-based Perkins School for the Blind and Sight Savers International in the UK. The program identifies future leaders and supports them through an intensive leadership program that is currently being transferred to be managed and run out of our African regional body based in Kenya.

When I put myself forward as a candidate for president of WBU, one of the platforms I stood on was to develop partnerships and future leaders. Since then, we have established partnerships with eye care health, education and international disability organisations. Within our membership, some of the larger, better resourced organisations have provided resources both financial and in kind to allow us to undertake projects and initiatives in a range of different areas of our work.

Partnerships in disasters and emergencies

Natural disasters, war and devastation in all parts of the world seem to be increasing. The world was shocked and mobilised when the tsunami hit South East Asia. We were faced with the terrible earthquake in Haiti which seemed to be quickly followed by disasters in Chile, the Pacific, China and more recently Pakistan, New Zealand and Japan.

Emergency response organisations generally do not have disability access at the forefront of their thinking, although some agencies such as the Red Cross are exceptions. In a country such as Pakistan, where food was dropped from planes and helicopters, it is not likely that many people with disability ran to pick up the parcels. Similarly, where food is distributed from central locations, providers are not likely to be in a position to ensure that blind people can find the queues. We all know that increased disability can be a result of such disasters.

Lessons learned

Consistent with good development practice, there have been some lessons learned about what works well in disability-inclusive emergency planning and response. For example:

- Local organisations are usually the best placed to understand the situation, who the local leaders are and what plans and responses have worked well in the past — often communities have a great deal of experience and stories passed down the generations about coping mechanisms.

- Supporting the development of local partnerships, for example between emergency coordination agencies and disabled people's organisations (DPOs) may be the ideal way to promote disability-inclusive approaches.
- For international organisations to be successful partners in local disaster-prone contexts, they need a good knowledge of the cultural and environmental situation.
- A coordinated approach that respects existing organisations and partnerships is more likely to succeed than if organisations work separately.
- Respect for local cultural values helps ensure that externally contributed benefits are appropriate. In some countries, such as Samoa during the 2010 tsunami, the value of 'collectivism' that drives Samoan society meant that people with disability were automatically moved out of danger first, before other community members.

There is a great opportunity now to ensure that people with disability are included at all stages of development, design, implementation, monitoring and evaluation of emergency preparedness programs as well as emergency responses. In a partnership context this means ensuring that emergency response organisations partner formally with DPOs to ensure that all disaster work is disability inclusive. This may include joint planning and implementation of projects and shared commitment to awareness raising within governments and communities about inclusive practices. This means recognising and valuing the lived experience of disability, not just including a token person on a reference group or consultation.

It is much easier to learn from our mistakes if we are working within trusting and collaborative partnerships. Earlier this year, when the tsunamis hit Tonga and Samoa, Australian Pacific Islands Disability Support (APIDS) responded by raising funds to assist people with disability and their families. We already have partnerships with DPOs in Tonga and Samoa and they both said that they thought it would be valuable for us to send over a small amount of money to assist people with disability and their families affected by the tsunami. Some funds were sent and were used wisely to assist families, but on reflection, we considered the benefits could have been much greater if we had supported the mainstream disaster response agencies to be more inclusive. In future, we think our role is not to provide the immediate rescue response, rather, to support our partners own advocacy efforts to ensure that any programs to rebuild and provide support to the community in an on-going basis must from the beginning include people with disability.

WBU has, over many years, been called upon for assistance in situations of natural disaster, human rights violations, and situations where people who are blind are forgotten as reconstruction and rights of victims are upheld. We have found that working in partnership with other specialised organisations and advocating for inclusive policies are the best way to make real and sustainable changes. We are currently developing a strategy on how and when we respond to disasters, to be considered by the executive in Melbourne in November. CRPD is of huge assistance in the area of disaster response. Many articles embody rights to all aspects of life and article 32 on international cooperation provides a framework for the major relief organisations to assist them in getting disability into their programs. The MDGs did not mention disability at the time they were developed. This deficiency has now been recognised.

The Haiti experience

The earthquake in Haiti provided an opportunity to make a real difference to future responses to disasters and emergency situations. It is essential that any strategy to build back better in Haiti narrows the socio-economic inequities experienced by people with disability. Incorporating the principles of universal design into all reconstruction will allow physical structures as well as other services to be accessible to the widest range of users. A commitment by NGOs to cooperate with each other on disability-inclusive practice will help to ensure that from a disaster, good practice can emerge.

The Global Partnership on Disability and Development (GPDD) and allies are working together to raise awareness and contribute useful information and tools in order to ensure that reconstruction efforts involve people with disability during all stages and that all rebuilt and newly built infrastructure as well as medical, economic, educational and socio-economic services systems are fully accessible to and usable by people with disability.

The members of the GPDD Working Group on Haiti Reconstruction have been the leaders in this initiative. The goal of their efforts is to provide development partners, UN agencies, governments, and other stakeholders, with planning strategies and tools to incorporate inclusive disaster recovery and reconstruction. They have produced guidelines and recommendations contained in the toolkit 'Haiti: Reconstruction for All' which are available online. The toolkit includes information on seven themes:

- physical environment;
- livelihood, employment and social protection;
- transportation and communication;
- education;
- health;
- capacity building of DPOs; and
- organisational and operational issues.

If these guiding documents are used, then a more comprehensive approach to disaster management will be possible.

A new partnership, Vision Alliance, came together quickly in response to the Haiti situation and illustrates the power of pooling efforts and resources. The International Agency for the Prevention of Blindness (IAPB), and the International Council for the Education for the Visually Impaired (ICEVI) came together with WBU to work to support people who are blind or have low vision, the eye care professionals and education and rehabilitation services and DPO providers in Haiti. We have agreed that our role is to assist in rebuilding, not provide emergency relief.

The blindness prevention, education, rehabilitation and advocacy programs related to blind and low vision persons were all dramatically affected by the earthquake. The Haitian Society of Aid for the Blind (SHAA) is the principal organisation in Haiti working for and with blind and low vision persons and much of its infrastructure was destroyed. The first priority therefore, was to stabilise SHAA so that it could provide necessary support on the ground through input into reconstruction plans.

A number of initiatives have been undertaken to address the situation. A team was put in place by the WBU North America/Caribbean Region to work with SHAA to restore the situation as it was before the earthquake and then to address longer-term issues of improving the situation for blind and low vision people, given that even before the earthquake they were the most disadvantaged in the western hemisphere. Concurrently, those in blindness prevention and eye care met to develop plans to restore programs and continue the critical eye care work. In addition, education professionals have been working with SHAA and the residential school for the blind that was damaged to rebuild the educational program. Through the linkages between ICEVI, IAPB and WBU, the different actors communicate their plans and develop them jointly where appropriate.

Conclusion

Finally, here are some principles that might help us, based on what we have learned over many decades. These are not new, we all know them, but I'd like to encourage you to remember them in your work.

- Partnerships between development agencies and DPOs are important in both emergency planning and response activities and long-term development activities.
- If our aid programs are undertaken within respectful and inclusive partnerships, our contribution is likely to be more substantial than if we work alone.
- Partnerships between international and local organisations are essential because responding to situations requires some knowledge about what has worked well in each setting as well as a commitment to flexibility and openness to learning — there is not any such thing as best practice that works in every place.
- If our aid programs recognise, respect and build on strengths in the countries where we work, and the strengths of the people we work with, we are more likely to make a lasting and relevant contribution.
- We should use every partnership as a learning opportunity so we can always be finding out how to do more of what works well.
- Where the situation is particularly difficult and challenging, trusting partnerships will be even more essential and need a longer term commitment.
- In preparing communities for disasters, inclusiveness is essential, and an understanding of existing cultural strengths and traditional skills will help to avoid undermining them.
- In emergency situations, a coordinated response which is inclusive of all people in a community is both essential and more likely to be effective.

I would like to leave you with two key messages:

- What is good for disability inclusion is good humanitarian practice.
- DPOs must be at the centre of all disability development programs and we must recognise the lived experience of disability and support DPOs to build their capacity and take their rightful place in their community.

Note

1 President, World Blind Union; General Manager, International and Stakeholder Relations, Vision Australia.

Disability and climate change: Understanding vulnerability and building resilience in a changing world

David Lewis, Strategic Programmes Director, CBM Australia
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Introduction

The vulnerability of poor nations, communities, families and individuals to the impacts of climate change is of growing significance. The World Bank estimates that 20 per cent of people living on less than $US1 a day worldwide are people with disability (Hope 2003), and that 82 per cent of people with disability in developing countries live below the poverty line (Elwan 1999). Policy development and interventions at all levels need to address the specific circumstances of people with disability in relation to climate change, together with those of their families.

The Intergovernmental Panel on Climate Change (IPCC) defines climate change as '*any change in climate over time, whether due to natural variability or as a result of human activity*' (IPCC 2001). In discussing the impacts of climate change, this article assumes the validity of observed and anticipated increases in average global temperature, extreme weather events, rising sea levels and changes to the timing and amount of rainfall.

This article also recognises that the impacts of climate change are intersecting with all key current concepts and priority areas of international development and poverty alleviation, including food, water and energy security, resilient livelihoods, resource distribution, public health, education, human rights, gender, ethnicity, protection, sustainability, national and regional security and migration.

Much is written about the impact of climate change on the world's most vulnerable groups of people — who it is anticipated will be disproportionately affected. However there is little literature to date that discusses the vulnerability of people with disability within these groups. Climate related reports such as the IPCC and the Human Development Report 2007-08 do not identify people with disability as requiring particular inclusion measures in adapting to their changing environment (Wolbring 2009).

It is anticipated that extra funds required for climate change adaptation and mitigation, will cause a significant shortfall in financial resources needed to achieve the Millennium Development Goals (Stern 2009).

The topic of 'Disability and Climate Change' is about equity and justice. It is about hope and innovation. It is about working together with people with disability to create awareness, understanding and solutions.

Impacts of climate change on people with disability

It is anticipated that climate change will cause increasing hardship for people with disability and other vulnerable groups. 'Quality of Life' is likely to deteriorate as the ability to adapt, livelihood opportunities and resilience are all anticipated to decline in a changing environment. Climate change is also likely to cause an increase in the incidence and prevalence of many disabling impairments. Key issues CBM has identified as impacting on 'quality of life' and well-being of people with disability as a result of climate change are:

1. decreasing food security and resulting malnutrition;
2. decreasing access to clean water, sanitation and hygiene (WASH);
3. increasing emergencies due to extreme weather events;
4. reducing access to infrastructure, shelter and basic services;
5. increasing displacement / migration;
6. inability to migrate due to disability; and
7. increasing human security and protection issues including those due to conflicts resulting from climate change

Decreasing food security and resulting malnutrition

In many communities, people with disability and their families already face food shortages on a daily basis due to their poverty. Climate change is projected to exacerbate food shortages and malnutrition in the world's poorest regions. We note that:

- Increases in the frequency of droughts and floods, including rising sea levels, are projected to cause decreases in local crop production, especially in subsistence sectors at low latitudes and in seasonally dry and tropical regions (IPPC 2007).
- Regional changes are expected to have adverse effects on food production from aquaculture and fisheries (IPPC 2007). Many of the world's poorest people depend on ocean and inland fish as a significant part of their diet.
- Malnutrition is estimated to cause approximately 20 per cent of impairments worldwide (DFID 2000). With increasing malnutrition, we must expect that more children, including those of parents with disability, will acquire disabling impairments.
- 'Fuel poverty' — of firewood and other cooking fuels — is an increasing cause of malnutrition in many parts of South Asia. It can be difficult to obtain adequate nutrition from uncooked food (Northcott 2007). As climate change and resource shortages advance it is anticipated that access to cooking fuel will be an increasing concern for vulnerable groups in many parts of the world.

Decreasing access to clean water, sanitation and hygiene

Many people with disability already face daily hardship in accessing adequate safe water for drinking, hygiene and sanitation. During this century, hundreds of millions of people, especially in the poorest regions, are expected to be exposed to increased water stress due to climate change (IPPC 2007). Changes in precipitation and temperature lead to changes in runoff and therefore water availability and quality. Increased temperatures will also affect the physical, chemical and biological properties of freshwater lakes and rivers, causing reduced quality. In coastal areas, sea level rises will exacerbate water resource constraints due to increased salinisation of groundwater supplies. This is already evident in many countries (IPPC 2007).

In regions with declining water quality and quantity, it is expected there will be increasing prevalence of water-borne diseases including those causing diarrhoea, with associated dehydration and malnutrition. An estimated 68 per cent of DALYs (Disability Adjusted Life Years) world-wide are attributable to unsafe and inadequate water for drinking and sanitation. With decreased clean water, an increase in resulting disability is expected, including in families where disability already exists (Murray and Lopez 1997).

Increasing emergencies due to extreme weather events

Research indicates that weather related disasters are increasing in number and severity. A study in Asia found these emergencies have increased by four times in the past 20 years, and that the number of people affected by them has risen, from an average of 174 million per year to 254 million in the same period (Oxfam Australia 2007).

Disasters and their aftermath have a huge impact on people with disability. They are among the most vulnerable in an emergency, sustaining disproportionately higher rates of morbidity and mortality, and at the same time being among those least able to access emergency support. In addition, there is a large tendency for people with disability to be *invisible* and overlooked in emergency relief operations (Choy 2009). When the emergency hits they may have difficulty reaching safe areas, become separated from family and friends which is a key to survival and coping, have trouble accessing vital emergency information, or lose assistive devices such as wheelchairs, crutches, prostheses, white canes or hearing aids.

In addition, people with disability who also belong to other minority groups based on gender, race, religion or ethnicity, may face added disadvantages in having their needs met. Inclusive practice in all relief operations are needed to ensure that response and service delivery is not fragmented but mindful of all sources of vulnerability (Kett and Scherrer 2009).

In the aftermath of a disaster, the damage to infrastructure caused by extreme weather events can reduce or completely remove access and safe mobility.

Reducing access to, infrastructure, shelter and basic services

In the world's poorest regions, climate change is causing an erosion of services, infrastructure and shelter. This can occur suddenly, due to an extreme weather event, or be slow and insidious.

As climate change places increased pressure on national budgets and resilient livelihood opportunities diminish, there are fewer resources available for affordable and accessible services and infrastructure to the poorest people. This is particularly so for those with disability who may be more reliant on these. Accessible basic health and other services may disappear. As an example, the loss of immunisation services will increase the risk of the poorest families, including those of people with disability, contracting preventable disabling diseases (WHO 2003).

In island and other coastal communities, sea level rise is expected to exacerbate inundation, storm surge, erosion and other coastal hazards. This will threaten vital infrastructure, settlements and facilities which support livelihoods (IPPC 2007). Clearly all these factors impact heavily on people with disability and their families.

Increasing displacement / migration

There are large numbers of climate refugees worldwide and within this group we know there are many people with disability. They are also frequently left behind in a degraded environment, when others in their family or community move on. The situation, as social and support networks disappear, can be devastating hardship.

An example of a significant climate migration is the movement of large numbers of people from the marginal Sahel zone of West Africa to densely populated coastal areas, due to regular crop failures in their home regions (Brauch 2002). Most people moving from rural to urban environments have no choice but to settle in slums, where housing and basic services are inadequate. They remain vulnerable to weather related risks, live in substandard and over-crowded housing, are prone to the spread of disease, have inadequate access to clean water, drainage, sanitation and waste removal, and often have few ongoing livelihood opportunities (Little and Cocklin 2010).

These conditions are all amplified for people with disability. They may face severe hygiene issues in accessing toilets, increased health consequences of living in a crowded degraded environment, and may have very limited social/support networks and livelihood opportunities as a result of decreased mobility and dislocation.

Poverty, dislocation and the breakdown of social structures are key factors which result in decreasing human security and protection. As the impacts of climate change increase, we must expect that persons with disabilities and their families will face increasing risks.

Human security and protection issues

During the coming century it is expected that scarce water and food resources caused by climate change, will cause conflict in a number of regions. For example, the current conflict in Darfur is said to be a struggle between nomadic and pastoral communities for resources that are becoming increasingly scarce as a result of the changing climate (Borger 2007). Such conflicts will increase the risks and hardships for people with disability. During conflicts, people with disability are additionally vulnerable due to difficulty moving to safety and because, as for other emergencies, they may be *invisible* to relief workers, who are unaware of their specific vulnerabilities.

Conflict is known to be a leading cause of physical and psychological disability (IPCC 2007). People may be unable to access appropriate interventions and assistive devices for health conditions and impairments which were either pre-existing or caused by the conflict. As a result their condition or impairment becomes a long term disability. Additionally, during conflict, health and social systems often break down, increasing the hardship for those who may be more reliant on them. Due to their vulnerability, all these issues directly impact people with disability and their families.

Conflict and other emergencies may also increase levels of social exclusion. An example of this was recorded in Sudan, where people with impairments caused by earlier leprosy infection were not allowed, by other refugees, into the camps — instead being sent to the leprosy village (Kett and Scherrer 2009). This example highlights the priority need for awareness raising within relief agencies and community, to ensure services are accessible for everyone.

Increasing impairments leading to disability

As indicated earlier, it is anticipated that many factors connected with climate change, will increase the incidence and prevalence of impairments leading to disability. This is due to both disease and injuries. Malaria is a key example of a disease which may cause disability. Roughly one in ten children will suffer from neurological impairment after suffering cerebral malaria, including epilepsy, learning disability, changes in behaviour, loss of coordination or speech impairments (Jones 2002). Warmer temperatures, with increased surface water and humidity, allow increased reproduction of mosquitoes which spread malaria and other diseases such as dengue and yellow fever. In addition, changing weather conditions facilitate epidemics in areas where malaria was not previously present. The populations in these 'new' areas lack protective immunity and are particularly at risk (IPPC 2007). Even by the year 2000, the World Health Organization (WHO) had estimated that climate change was responsible for six per cent of malaria in some countries (WHO 2002).

Including persons with disabilities

Nothing about us without us

The issue of climate change and its role in increasing the poverty and vulnerability of the world's poorest people, including those with disabilities, is of enormous significance to this generation. Persons with disabilities are in the best position to understand their own situations and be part of seeking solutions to the problems they face. We need to adopt the slogan '*Nothing about us without us*' and work together in mutual learning and empowerment, to ensure that their strengths and vulnerabilities are represented in all key international, national and local forums, strategies and research on climate change.

Recognising vulnerability and capacity for adaption

Vulnerability to the effects of climate change will depend on the resilience of each individual and community and their ability to adapt. Critical factors shaping the resilience and adaptive capacity of individuals, households and communities are their access to and control over natural, human, social, physical, and financial resources (Care International 2009). People with disability are typically among the most 'resource poor' within a community, due to poor education, lack of income, social exclusion and limited access to decision-making authorities. Therefore, as for other marginalised groups, they will have little access to or control over those resources which would facilitate adaption.

Some key principles and actions

In outlining a response, we put forward some key principles and some actions to start with:

Principles

- The central role of people with disability (and their carers) in representing their own vulnerabilities, needs and solutions in their situations.
- A 'Rights Based' Approach, in line with the United Nations Convention on the Rights of People with Disabilities.
- A 'Twin-track' Approach, which promotes both 'specialist disability initiatives' designed to include and empower people with disability and the 'mainstreaming' of disability inclusion into all policies, strategies and activities.
- The use of the WHO Community Based Rehabilitation Matrix as a framework outlining the right of people with disability to health, education, livelihood, social inclusion and empowerment; with the associated guiding principles of inclusion, participation, self-advocacy, accessibility and sustainability.
- The critical need to end the 'cycle of poverty and disability'. There are strong links between extreme poverty and disability — each resulting from the other. Ending the cycle must also include addressing discrimination and negative attitudes which create barriers and exclusion, exacerbating the hardships people with disability may face.

Actions

Arguably, 'climate change' represents the most overwhelming issue currently facing the entire global population. There are no single or simple answers. The development community needs to work together with people with disability to build strong, sustainable and innovative solutions and actions. The actions we list here are just a start.

- Climate funds are being created to assist in mitigation, adaptation and building resilience in the poorest and most affected countries, eg, ‘Fast Start Financing for Climate Change’. Strong advocacy by and with people with disability is needed to ensure disability inclusion is a key criterion in all ‘climate funds’.
- The evidence base concerning the vulnerability of people with disability in weather related emergencies, and key factors which create resilience, need to be greatly strengthened, with key messages disseminated.
- Evaluations of both emergency and development programs, in areas affected by a changing climate, need to clearly include disability in their terms of reference. The lessons learned, in relation to both ‘specialist’ and ‘mainstreamed’ activities need to be clearly documented and shared.
- In the reconstruction phase following severe weather and other emergencies it is essential that universal accessibility standards are applied. This is important for all public buildings and spaces, water and sanitation points and for the homes where people with mobility disability live.
- ‘Disaster Risk Reduction’ activities at all levels need to specifically include people with disability as a vulnerable group.
- This article has emphasised the link between poverty and vulnerability. Along with ensuring access to health and education, the inclusion of people with disability and their families into mainstream livelihood, food production, water, sanitation & hygiene (WASH) and energy programs in both rural and urban areas, is an essential key to building resilience.
- We need to be part of advocacy encouraging governments, the private sector, civil society and individuals in all parts of the world to reduce carbon emissions. We need to model responsible use of the world’s resources ourselves.

The intersection between ‘disability and climate change’ requires more than an advocacy strategy. Working together with people with disability, we need to create a ‘movement’ of understanding and action, to ensure their full participation and inclusion in the mainstream development process, as it adapts to the new paradigm climate change is bringing.

References

Borger, J 2007, ‘Climate Change and Conflict’, *The Guardian*, 11 May, London.

Brauch, H 2002, *Climate Change and Conflict Prevention,* German Federal Ministry for the Environment, Nature Conservation and Nuclear Safety.

CARE International, 2009, *CARE’s Climate Vulnerability and Capacity Analysis Handbook,* http://issuu.com/careandclimatechange/docs/care_cvcahandbook, accessed 4 March 2011.

Choy, R 2009, ‘Disasters are always inclusive: Vulnerability in humanitarian crises’, *Development Bulletin*, Special Issue No. 73,April 2009, Development Studies Network, ANU, Canberra.

DFID (Department for International Development) 2000, ‘*Disability, Poverty and Development*’, DFID, UK, http://handicap-international.fr/bibliographie-handicap/4PolitiqueHandicap/hand_pauvrete/DFID_disability.pdf, accessed 4 March 2011.

Elwan, A 1999, ‘Poverty and Disability; a survey of the literature’, *The World Bank, Social Protection Discussion Paper Series* (1999): 9932.

Hope, T 2003, ‘DISABILITY: Aid Groups Call for A UN Convention To Protect Rights’, UNWire, 14 February.

IPCC (Intergovernmental Panel on Climate Change), 2001, *Third Assessment Report. Working Group II. Climate Change 2001: Impacts, Adaption and Vulnerability*. http://www.grida.no/publications/other/ipcc_tar/, accessed 4 March 2011.

IPCC, 2007. *Fourth Assessment Report. Working Group II. Climate Change 2001: Impacts, Adaption and Vulnerability*, http://www.ipcc.ch/publications_and_data/ar4/wg2/en/contents.html, accessed 4 March 2011.

Jones, I 2002, *Neurological Damage from Malaria* http://malaria.wellcome.ac.uk/doc_WTD023883.html, accessed 4 March 2011.

Kett, M and Scherrer, V 2009, *The Impact of Climate Change on People with Disability*. Report of e-discussion hosted by The Global Partnership for Disability & Development (GPDD) and The World Bank (Human Development Network — Social Protection/Disability & Development Team). http://www.gpdd-online.org/media/news/Impact_of_Climate_Change_on_Disability-Report-Final_012010.pdf, accessed May, 2010.

Little, L and C Cocklin 2010, ‘The Vulnerability of Urban Slum Dwellers’, In *Global Environmental Change and Human Security,* Matthew, R, and Barnett J (eds), The MIT Press, Massachusetts.

Murray, C and A Lopez 1997, ‘Global mortality, disability, and the contribution of risk factors: Global Burden of Disease Study’, *The Lancet*, Vol 349, http://old.spread.it/Volume/chapt04/add_04/Ref_04006.pdf, accessed 4 March 2011.

Northcott, M 2007, ‘*A Moral Climate*’, Darton, Longman &Todd Ltd, London.

Oxfam Australia Website, www.oxfam.org.au, accessed 4 March 2011.

Stern, N 2009, *A Blueprint for a Safer Planet,* Vintage, Random House, London, UK.

WHO (World Health Organisation) 2003, *Climate Change and Human Health — Risks and Responses. Summary,* http://www.who.int/globalchange/climate/summary/en/, accessed 4 March 2011.

WHO, 2002, *World Health Report 2002 — Reducing Risks, Promoting Healthy Life.* http://www.who.int/whr/2002/en/, accessed 4 March 2011.

Wolbring, G 2009, ‘A Culture of Neglect: Climate Discourse and Disabled People’, *M/C Journal*, 12(4), http://www.journal.media-culture.org.au/index.php/mcjournal/article/viewArticle/173/index.html, accessed 4 March 2011.

World Bank, 2007, *Energy use (kg of oil equivalent per capita),* http://data.worldbank.org/indicator/EG.USE.PCAP.KG.OE, accessed 4 March 2011.

Notes

CBM is an international development organisation committed to improving quality of life of the world’s poorest people with disability and those at risk of disability. CBM seeks an inclusive world in which all people with disability enjoy their human rights and achieve their full potential.

The primary indicator used to summarise the burden of premature mortality and disability (including temporary disability) is the disability-adjusted life year (DALY).

The role of culture and ethnicity in disability inclusive development: Lessons from Australia

Sibylle Kaczorek, Executive Officer, National Ethnic Disability Alliance

The National Ethnic Disability Alliance (NEDA) is the national peak organisation representing the rights and interests of people in Australia with disability, their families and carers, from non English speaking background.

The alliance was formed 15 years ago by individuals and state organisations involved in the advocacy for people with disability from non English speaking backgrounds after the need for a national voice able to respond to government policy and legislation had been clearly identified.

The lessons from NEDA's experience over the last 15 years have considerable relevance to international development work in general and to disability-inclusive development in particular. Their experience highlights the impact of culture and ethnicity on the ability of people with disability in accessing disability-related services. Yet today, culture and ethnicity remain largely unacknowledged in research, reporting and disability support.

The impact of culture

We are all cultural beings — our culture shapes how we see the world and make sense of it. Culture influences our behaviour, values, norms and interactions. It is constantly changing and responding to shifting environments and circumstances. While Australia includes people from a large number of different cultures, the dominant culture remains Anglo–Australian.

Ethnicity, on the other hand, is used to describe a persons' sense of affiliation or identity and it is used when people share cultural commonalties including language, rituals, food, dress, faith, etc.

Based on its experience, NEDA highlights how cultural ignorance or cultural blindness has negative effects on groups outside the dominant culture. Numerous reports, presentations and research have demonstrated that unless there is recognition of the existence of other cultures and their specific situation, viewpoints and needs, there will be a failure in data collection, planning and policy development to address equity issues. This failure results in people from cultures other than the dominant Anglo–Australian to lag behind in socio-economic life indicators. It contributes to social exclusion.

Relating this to people with disability, NEDA found that people with disability from non English speaking backgrounds experience a higher rate of poverty and unemployment and do not access services for people with disability at a rate comparable to that of their English speaking counterparts. These services include education, supported accommodation and employment.

Why data matters

There is little debate over the need for data to understand specific situations. There is a difference between so called *hard data*, information that can be quantified and measured such as statistical information, and *soft data*, which refers to anecdotal information that adds context and can tell a story. Albert Einstein famously noted 'Not everything that counts can be counted, and not everything that can be counted counts'. This should remind us that figures alone do not tell a complete story and that contextual information, actual life experiences, history and broader issues including policy and legislation, are also part of the story.

In Australia, we have a disproportionate wealth of soft data but hardly any hard data on the lives of people with disability from non English speaking backgrounds. Nor do we have information on their families and carers. The hard data that is available is inadequate in a number of ways.

In Australia, the two key sets of statistical data that provide us with information are the Census of Population and Housing (Census) and the Survey of Disability, Ageing and Carers (SDAC), both collected and analysed by the Australian Bureau of Statistics (ABS).

The Census has the potential to provide an immensely rich source of data on ethnicity in Australia. It not only collects country of birth, but other ethnicity indicators including language spoken at home and country of birth for one or both parents. With regard to disability the Census has limitations. Its measure of disability is 'need for assistance'. This is not comparable with the SDAC data and thus limits an informative merging of the two sets of data for analytical purposes.

The SDAC is often regarded as the most authoritative survey of disability in Australia. The survey involves a sample size of close to 40,000 people and is weighted to enable a degree of representativeness and comparability.

The 2003 SDAC used a very broad definition of disability. It is on the basis of this survey that the ABS concluded that one in five Australians (or 4 million people in 2003) reported a disability. The limitations of the 2003 SDAC relate to ethnicity. The single ethnicity indicator in the 2003 SDAC is Country of Birth. Despite this information being included in the SDAC summary of results the ABS failed to report on key characteristics for people with disability who were born in countries other than Australia, in particular non English speaking countries.

NEDA's own data analysis has demonstrated that there are around one million people with disability in Australia who come from non English speaking backgrounds.

In the 2009 SDAC an additional ethnicity indicator was included — language spoken at home. This is a step forward but does not go far enough. Since the results from the survey collection have not yet been released, new findings may emerge after its release.

The reduction of ethnicity to Country of Birth and Language is extremely narrow and denies recognition to people of second and subsequent generations of non-Anglo cultures. Most people would agree that the lives, lifestyles and socio-economic backgrounds of those born in Australia with one or both parents born in a non English speaking country would be significantly influenced by the experiences of their parents.

Effectively, this denial means that the life experiences of people who differ from the dominant Anglo-Australian culture in their visual appearance, cultural celebrations and behaviours, or hold distinctly different cultural values, are non-distinguishable in the data collected. Once, this kind of approach was termed cultural assimilation.

Links to policy and legislation

Current examples in Australia demonstrate how a lack of culturally respectful and informed data continues in government policy and planning. The National Disability Agreement (NDA), as recently effective as January 2009, does not mandate data collection on people from non English speaking or culturally or linguistically diverse backgrounds.

The NDA states that it 'provides the national framework and key areas of reform for the provision of government support to services for people with disabilities' (COAG[1] 2008:1). In a footnote under performance indicators it states 'subject to the development of the data and an agreed method of disaggregation, performance indicators will also identify people with disability from culturally and linguistically diverse backgrounds within the measure' (COAG 2008:6). There is no process or timeframe provided by which this data development is to occur, keeping in mind that the next SDAC will be collected in 2015.

While the National Disability Strategy (NDS) exists only in draft form at this stage, it equally fails to effectively plan for people with disability from non English speaking backgrounds.

The NDS provides an opportunity to include specific policy strategies, targets, and outcomes for each population group throughout each policy area. NEDA continues to argue that this is a question of government accountability. Equitable outcomes for people with disability from non English speaking backgrounds are not a current reality regardless of which set of socio-economic or quality of life indicators are applied.

It thus can reasonably be inferred that policy, project and program planning specifically for people with disability from non English speaking backgrounds will not occur in a coordinated or strategic way in the near future.

Application of lessons to disability inclusive development

Considering the situation in Australia, lessons can be drawn for consideration by the disability inclusive development community.

Cultural sensitivity and inclusion can be practiced in a number of ways. Initially, agencies need to reflect on the cultural assumptions embedded in their approach to disability-inclusive development and question if such assumptions are relevant for the respective country and people they aim to work with.

At this early stage it would be advisable to involve people with disability from their respective target country in their program planning and design. The options here are to work with people with disability and/or their representative organisations (DPO) in the respective country directly. If resources will not permit this at an early planning stage it is advisable to work with people with disability from their respective target country who are resident in Australia. By utilising its existing state and territory networks NEDA can assist in this process.

The second consideration is to identify any minority ethnic or faith based groups within the target country. Sensitivity needs to be developed to ensure that any such groups of people with disability and/or their representative organisations are considered in the design, planning, implementation and monitoring stages of any programs. Specific strategies, targets and outcome measures need to be developed to guarantee equitable outcomes for all groups within the target country. This demands careful development and collection of data.

It may be that attention to minority groups will identify patterns and trends that were not previously considered or thought of. Dedicated research led by minority groups would assist in understanding differing lived experiences. The difference in languages and/or dialects is a case in point.

A project on mental health found an alarming number of reported misdiagnosis because interpreters are not relaying the appropriate information to mental health staff. As one consumer said:

> people can't explain themselves clearly and carers don't give the right information - if the information doesn't meet their criteria they don't get the right diagnosis (consumer) (*Multicultural Mental Health Australia* 2004:15)

The same project found that consumers pointed to stigma and lack of knowledge due to inaccessible information as a key barrier to services and support (Multicultural Mental Health Australia 2004:16) and that:

> people avoid services because there is a lot of stigma (consumer)

The CRPD is unique in that it is both a development and a human rights instrument. The Convention incorporates a development framework and deals with empowering people with disability. This framework will assist in involving people with disability from minority groups who arguably are often among the poorest and most marginalised, even when compared to other people with disability within that country.

Human Rights inconsistency

Any discussion on disability-inclusive development needs to address the inconsistency applied to Australia's migration policy versus disability-inclusive development.

The administration of the Migration Act and migration regulations have meant that people with disability applying for permanent migration into Australia have been effectively excluded. This also applies to people with disability within the family of a prospective applicant. In addition, the Disability Discrimination Act 1992 is exempt from the Migration Act 1958 as it relates to the health assessment. This migration process also applies to people seeking protection in Australia under the refugee convention.

Circumstances and reasons for migration or seeking asylum vary greatly and NEDA is aware that in some circumstances applicants make the very difficult decision and leave a loved family member with disability behind in their country of origin or country of last residence. Such circumstances are traumatising for all family members involved and considered as a last resort when there appear to be no alternative options available.

In such circumstances the countries where the person with disability remains may not have the resources and programs to effectively care for the person in the absence of critical family members' availability. These situations create hardship for the respective countries in addition to the traumatic effects on the people involved.

At the same time, the Australia Government is investing $30.2 million over four years from 2010–11 to improve access and social economic opportunities for people with disability. While the Government is to be commended for identifying people with disability in its international development work, one cannot escape the inconsistency between the approaches taken in regards to migration and disability-inclusive development.

NEDA believes that the disability-inclusive development community will contribute to a consistent human rights approach by supporting the campaign for a more equitable migration approach in Australia, including the full application of the Disability Discrimination Act to the Migration Act.

NEDA offers its knowledge and experience to work with the disability-inclusive development community to develop good practice approaches and models.

To contact NEDA, please email: office@neda.org.au.

References

COAG, 29 July 2010, 2010–2020 *National Disability Strategy, An initiative of the Council of Australian Governments*, Australian Government http://www.billshorten.com.au/uploads/billshorten/National_Disability Strategy.pdf, accessed 24 January 2011.

COAG, 29 November 2008, National Disability Agreement, Council of Australian Governments http://www.dhcs.act.gov.au/data/assets/pdf_file/0019/103942/National Disability Agreement.pdf, accessed 24 January 2011.

Multicultural Mental Health Australia 2004, Reality Check: culturally diverse mental health consumers speak out, http://www.neda.org.au/files/RealityCheck.pdf , accessed 24 January 2011.

Note

[1] Council of Australian Governments

Disability-inclusive development for Australian Aboriginal People

Damian Griffis, Executive Officer, Aboriginal Disability Network

The First Peoples' Disability Network Australia is the first national Indigenous disabled people's organisation in the world. We are very proud of that. I know that friends in Canada have some provincial networks as has New Zealand but we are the first national body as far as we are aware. I want to present some facts about disability in Aboriginal communities and government service provision, based on what I see when I am out in communities.

It is believed that the prevalence of disability among Aboriginal people is twice that of the mainstream Australian population and that at least 37 per cent of our people have some form of disability or long-term health condition. What is most concerning about this is that it does not include psychological disability or mental illness. There are plenty of Aboriginals who will tell you that things like depression, anxiety and post traumatic stress disorder are normalised in many of our communities, so it's a very conservative figure.

Identifying disability in Indigenous communities

There is very little reference material on Aboriginal people with disability and very little research into this area. If it is done, it's usually done from a health perspective and this perspective is problematic. Many Aboriginal people with disability don't recognise they have a disability which can be a reason why some people fall through the gaps in government services. Aboriginal people with disability are far more likely to acquire their disability due to preventable health conditions such as diabetes which under disability discrimination law is a disability in itself. If you don't get support and health care early enough it can result in amputations and other disabilities resulting from the amputation. Aboriginal people are very likely to experience multiple barriers to getting assistance. They are unlikely to have a job and very unlikely to have accessed the education system — we meet many Aboriginal people with disability who have never been to school. It is unusual for them to have accessed government services.

Interestingly, in traditional Aboriginal languages that I have come in contact with, there is not a comparable word for disability. This suggests that disability was an accepted part of the human experience. Certainly, in some of our more traditional communities it may have been that people with vision or hearing impairment were considered to have special status within their community. Things like telling stories or having visions are normal cultural narrative in many of our communities that in other cultures may be labelled as schizophrenia.

Identifying disability and ability to access services depends on what part of the country we are talking about. In parts of the country, where people had to move around following water sources, they may have found it more difficult to support a person with disability. This may have resulted in infanticide. In more permanent dwellings in coastal communities, it was probably easier to support a person with disability.

Supporting Indigenous people with disability

Most Aboriginal people with disability are supported within their family and community environment. So, even a notion of service is quite a foreign or odd concept in many ways. Why would you go outside your own community to seek support? The other thing that must be said is that the medical model of disability has had a profoundly negative impact on the lives of many Aboriginal people with disability. Here in Australia we are familiar with the 'Closing the Gap' campaign which I feel is only doing part of the job.

Let me give you some examples. An old fellow goes to hospital with complications from diabetes and ends up having an amputation. When it is over he gets wheeled out the front of the hospital where he is picked up by his family and taken back to his community to a house that he can't move in and out of. You get a tick for the health intervention but there is no whole of life perspective which would ensure the old man retained his mobility.

Hearing impairments among children are a very common problem. Children may get a simple procedure to fix it but as many of them may not have been able to hear for three, four or five years they have acquired a serious learning disability. Again, we get a tick for the successful medical intervention but a more long-term approach has not been taken. There is no remedial class at school to help the child catch up. Unfortunately, disability is rarely mentioned in the 'Closing the Gap' campaign. If it is, it's usually from a medical perspective.

Issues affecting Indigenous disability

There are a number of social factors that contribute to the higher prevalence of disability among Indigenous communities. People should be aware of some of these factors. These are:

- Lack of good quality healthcare and health prevention programs, particularly for young mothers when they are pregnant.
- Lack of access to appropriate housing in urban areas including clean water and sanitation. You don't have to go far from Darwin to see people living without hot water or electricity.
- Lack of family resources. I have encountered on too many occasions, Aboriginal people with cerebral palsy, for instance, who are crawling around on the floor. They are not necessarily abused or neglected but because the family lacks resources, they don't get the particular supports they need.
- When the whole community struggles, having a disability is not seen as anything particularly different because everyone in that community struggles.

- Greater exposure to violence and abuse. Acquired brain injury is a particular type of disability that has a high prevalence in our communities.
- The psychosocial impact of colonisation. This is an area that is not well understood and the Mental Health Service has real difficulty knowing how to address it.
- Dispossession from land and the pain associated with that. I have certainly met elders around the country who talk about a deep pain associated with lack of access to their river, and the deep mental illness this can cause. So it is an issue of major concern. Often Australian farmers will talk about the sadness they feel after being four or five generations on the family farm and having to move off the farm because they can't make it work economically for them any more. I don't understand why the same rules don't apply to Indigenous people.
- A growing problem around substance dependence.

Undiagnosed disabilities

We have high rates of undiagnosed disabilities. We see examples of the Aboriginal kid in the back of the classroom who turns out to have a hearing impairment but ends up getting frustrated in the classroom and gets expelled only to find out later, he had a disability. It is common to rush to judge that child as another 'bad black kid' and not properly looking deeper at their circumstance and the possibility of a disability or a mental health problem. There is clearly a high rate of undiagnosed mental illness. But I say that with great trepidation because I would be nervous about a rush to over diagnose mental illness in Aboriginal communities. It's a highly complex area.

Access and other challenges

Aboriginal people with disability have different experiences depending on where they live and the availability of services — a very obvious thing to say but something that plays out dramatically in the Northern Territory and in remote parts of New South Wales, Queensland and Western Australia, where the practicalities of accessing support are quite challenging. It may be that in some parts of remote Australia, the only form of transport is a plane, but planes are not accessible to most Indigenous people. So, there are challenges around that kind of thing.

Aboriginal people are frequently unable to access their most fundamental human rights — access to shelter, to education, employment, or health care. Aboriginal people have very poor access to information. This is a common barrier and a common complaint for many of our members and many Aboriginal people and their families. Information has to be more than brochures with pictures of goannas on them and nice Aboriginal motifs. It requires a concerted outreach approach where people get to learn and understand what is meant by the disability service system.

The other thing I want to make clear, is not necessarily about creating service systems as a solution. I am nervous when I hear people promote that idea because it's not necessarily what communities want or what they need. An example I can give you is a very small, remote community in western New South Wales — it's 150 kilometres north of Burke, on the Queensland border.

There was no service provision whatsoever in this community other than some nuns who came up from Burke and put on a meal once a week. When we reported that to government authorities, they immediately wanted to put in a home care program and a local area co-ordinator. All that they needed was a wheelchair accessible bus so they could go down to Bourke, do their shopping and go to doctors appointments.

I also have criticism of the Aboriginal sector. Disability is not an issue that's on the Aboriginal rights agenda in any substantive way. This is not a-blame-the-government exercise. There is much to do in the Aboriginal sector particularly around some of the issues around stigma. For example, I have had prominent people in communities, saying 'there is no Downs Syndrome in our communities' but this may be based on something as simple as the community having a real fear that their child will be taken away if it is identified as a child with disability.

Sadly, racial discrimination is still a reality in the disability service system. Where there are large Aboriginal populations only four or five Aboriginal people actually access the local disability service yet they make up 90 per cent of the population with disability. Racial discrimination remains a problem for Aboriginal people with disability and has become more sophisticated. It has become more like the person turning up to the post office and getting to the front of the queue and suddenly the service is not as great as it was a moment ago.

There are very low rates of access to individual advocacy services. This is an area that needs immediate reform. While there are have been some really positive things happening in the last few years often this is the work of volunteers with no resources to put this issue on the agenda. But we do have a new national peak organisation that will be launched in May 2011.

Disability networks

There are networks of Aboriginal and Torres Strait Island people with disability in Queensland, New South Wales, South Australia, and Victoria that are funded by their respective governments. Invariably, they are single-person operations which place incredible demands on individuals. So, our job is to build the capacity of those state and regional based networks, to launch a national leadership program for Aboriginal and Torres Strait Island people with disability so they can have their voice heard and speak up with confidence, and to engage in an advocacy program that immediately tries to address some of the urgent individual matters that come across our desk every day.

Employment

Currently, there are only two supported employment programs for Aboriginal people with disability in the whole of Australia. On Tiwi, there is an artist cooperative where a number of artists with disability are doing exceptional work and in New South Wales there is a supported program for

Aboriginal people with disability. Clearly there is a long way to go.

So, the unmet need in this area is extraordinary. What I find most challenging is that change is very slow. Many Aboriginal people with disability have been speaking about this for a lot longer than I have and we are yet to see significant change but at least the advent of a new national body will move the agenda forward in some ways.

WHO and the medical colonisation of psychosocial disability

David Webb, International Representative, Australian Federation of Disability Organisations

Introduction

In September 2010, the World Health Organisation (WHO) released *Mental Health and Development: targeting people with mental health conditions as a vulnerable group*[1] describing it as a ‘call to action to all development stakeholders ... to focus their attention on mental health’[2] and claiming that it ‘makes the case that people with mental health conditions are a vulnerable group deserving targeted attention in development efforts’ (p vii). The report is at least partly in response to the UN Convention on the Rights of Persons with Disabilities (CRPD):

> The human rights-based approach to development recognizes the protection and promotion of human rights as an explicit development objective. This approach, coupled with the United Nations Convention on the Rights of Persons with Disabilities (CRPD), 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 (p.xxv).

There is much to be commended in this report, but a closer reading reveals another example of WHO’s participation in the medical colonisation of psychosocial disability. We look first at how WHO is locked into the western, very medical model of psychosocial disability that lies at the foundation of this new colonialism of the 21st century. We note that WHO is remarkably silent on the most critical human rights issue for people with psychosocial disabilities — the elephant in the room of involuntary medical treatment. Finally, we look at what the WHO says elsewhere about the rights of people with psychosocial disability and find that the organisation seems to be living in a pre-CRPD world.

The medical model of psychosocial disability

WHO is very careful in the language it uses in *Mental Health and Development* but a closer reading reveals that they still see psychosocial disability primarily through a medical lens. WHO now avoids referring to ‘mental illness’ completely. The use of the term ‘disorder’ is only found in conjunction with specific psychiatric labels, such as bipolar disorder etc (eg. p.40). Perhaps this language is avoided by WHO because it is provocative, and indeed offensive language to many with psychosocial disability. Rather, the preferred terminology is ‘mental health condition’. This follows the concept of a ‘health condition’ in the ICF[3] which has been criticised by people with disability because it puts an ICD-10 medical diagnosis at the centre of WHO’s definition of disability.

The term psychosocial disability does not appear at all even although this is the preferred term of the people themselves and is now generally accepted elsewhere throughout the UN. The preferred terminology reflects one of the key principles of the social model of disability that underpins the CRPD, which is that a medical diagnosis becomes a disability when you experience discrimination because of that diagnosis. WHO is well aware of this but chooses not to use it.

There is an attempt in the report to de-medicalise psychosocial disability, but it only goes part of the way. Phrases such as ‘diagnosable mental health condition’ (p.30) and the frequent mention of symptoms and treatment, including ‘treatment gap’ (pp.16, 24, 35), indicate its medical bias. Statements such as ‘Children with sub-clinical mental health conditions (mental health problems not meeting criteria for psychiatric diagnoses)’ (p.20) establish psychiatric diagnosis as the standard for what constitutes a mental health condition, and therefore a psychosocial disability.

Of particular concern are statements like ‘The treatment of mental health conditions is as cost effective as retroviral treatment for HIV/AIDS, secondary prevention of hypertension, and glycaemia control for diabetes’ (Box 4, 36). This sounds perilously close to the now discredited ‘chemical imbalance of the brain’ hypothesis of mental illness.[4] It is also of concern that the report claims that ‘Patients must have access to essential psychotropic medications’ (Box 5, 37) without any discussion of the hazards of these medications — especially when they are forced on people without their consent.

If you look at some of the other WHO mental health and development programs, such as its Mental Health Gap Action Programme (mhGAP) then it is clear that psychosocial disability is still seen very much in terms of contemporary western psychiatry — ie. mental illness, psychiatric disorder, diagnosable symptoms, medical treatments and so on. The mhGAP Intervention Guide targets depression, psychosis, schizophrenia and bipolar, all of which are contested diagnostic categories in many western societies, something that does not get mentioned in any WHO literature on mental health and development.

This report is a step towards understanding psychosocial disability through the lens of the social model of disability and the CRPD, but it is only a small step. Much more is required, especially when you consider that the medical label of ‘mental illness’ is so often the basis for discriminatory legislation against people with psychosocial disability.

Involuntary treatment — the elephant in the room

The *only* mention of involuntary treatment in *Mental Health and Development* is:

> For example, they can encourage the establishment of mechanisms within the justice system to prevent abuses in relation to involuntary admission and treatment in mental health facilities (p.50).

Given that involuntary treatment is the most serious and urgent human rights issue for people with psychosocial disability, it seems an extraordinary oversight. Those of us familiar with the Department of Mental Health and Substance Abuse at the WHO recognise that this is no accidental oversight. On the contrary, their silence on this critical matter is the elephant in the room, always present but never mentioned.

The WHO clearly endorses involuntary psychiatric treatment, as can be seen through its endorsement of South Africa's Mental Health Care Act:

> Development stakeholders can catalyze human rights reform through encouraging the development and implementation of policies and laws that comprehensively address mental health and human rights.[5]

If you look at the South African Act you will see that, like most mental health legislation around the world, it gives legal sanction to the detention and involuntary medical treatment of people with psychosocial disability on the basis of 'mental illness' when that the person is deemed to be a potential danger to themselves or others (Section 9 of the Act). Such discrimination violates the CRPD. This becomes apparent when you consider that other people who might be at risk of danger to self or others are not subject to the same infringements of their rights. People with psychosocial disability (ie. 'mentally ill') are not treated in South African law on an equal basis as others, as required under the CRPD.

It is worth noting that the Preamble of the South African Act refers to the South African Constitution that 'prohibits against unfair discrimination of people with mental or other disabilities', which suggests that it allows for the curious notion of 'fair discrimination' when it comes to people with mental or other disabilities.

WHO literature on mental health and human rights

The WHO mental health literature includes various documents on human rights, the major one being its *Resource Book on Mental Health, Human Rights and Legislation*. Note its date of publication, 2005, is prior to the adoption of the CRPD by the UN General Assembly in 2006 but also, significantly, towards the end of the five years of negotiations leading up to the CRPD. The WHO knew that the CRPD was coming when it published its Resource Book. While not surprising that the Resource Book does not mention the CRPD, it is surprising that it remains WHO's primary reference on mental health and human rights four years after the UN's adoption of the CRPD.

The Resource Book is largely based on an earlier WHO document called the *UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care* (1991), commonly known as the MI Principles. Many countries, including Australia, have adopted MI Principles as the human rights standard for their mental health legislation, policies and programs.

The MI Principles have been criticised by people with psychosocial disability ever since they were released because of their low human rights standards and because people with psychosocial disability were not consulted during their drafting. Since the adoption of the CRPD, there have been calls for the MI principles to be either withdrawn or revised to make them consistent with the CRPD. It is pleasing to see the WHO finally recognised this in *Mental Health and Development*:

> The UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (1991) were developed without significant involvement by people with mental health conditions. As a result, the credibility of the Principles was diminished in the eyes of many, and resulted in a call to have them revoked. In contrast, the UN Convention on the Rights of Persons with Disabilities was drafted with the active participation of disability organizations, including mental health service user representatives. The Convention has been embraced widely by the disability movement as the universal standard for the human rights of all people with disabilities, and has taken precedence over previous instruments, including the UN Principles. (p.15)

Despite this, the *Resource Book on Mental Health, Human Rights and Legislation* continues to be cited by WHO as their recommended reference, with no indication as to when it might be revised or replaced. This is urgent as the CRPD is already four years old and the Resource Book**,** and the MI principles on which it is based, represent a significantly lower human rights standard than the CRPD. It is essential that people with psychosocial disability and their organisations have a major leadership role in revision or replacement. There should be 'Nothing About Us Without Us.'

The medical colonisation of psychosocial disability

In many western countries, the excessive medicalisation of psychosocial disability is a major controversy that is hotly debated, especially, but not only, when it occurs in partnership with involuntary psychiatric treatment. WHO is well aware of this controversy but chooses to remain silent.

This situation is sometimes described as the medical colonisation of psychosocial disability — an apt terminology when this very medical, very western model is so heavily promoted in developing countries. WHO is at the forefront of these efforts to spread the influence of modern, western psychiatry, which also includes some major Australian organisations such as Asia Australia Mental Health (a partnership of Melbourne University, St Vincent's Mental Health and the Nossal Institute), Mental Health First Aid International (originating in Melbourne, but now exported to Hong King, Singapore, Japan, Cambodia and Thailand), and the Nossal Institute in partnership with Basic Needs UK.

In *Mental Health and Development* a distinct colonialist attitude can be seen, an attitude that western, medical concepts of psychosocial disability are superior to other local, traditional and indigenous ways of understanding extreme psychosocial distress. On page 9, the report gives some examples from Afghanistan, Oman, Thailand and Turkey of stigmatising superstitions and prejudices against psychosocial disability. It is difficult to read these examples without thinking they show the ignorance of non-medical (and non-western) ways of understanding madness. The report fails to balance this with any examples of non-medical and non-western ways of understanding psychosocial distress that many people find useful, helpful and healing. One notable example of this is in New Zealand where traditional Maori values and ways of understanding psychosocial distress are respected and integrated into New Zealand's mental health system.

The colonialist attitude can also be seen in the lack of any critical analysis by WHO of the stigmatising prejudices to be found in the western, medical model that they endorse. Modern (western) psychiatry is under serious attack for its flawed diagnostic system, its frequently hazardous treatments and its participation in human rights violations. The challenge is being led by users and survivors of psychiatry but includes other experts from a broad range of disciplines, such as psychology, social workers, mental health practitioners and a growing number of dissenting voices within psychiatry itself. WHO chooses to defend the status quo of modern psychiatry by remaining silent.

This is of particular concern in the context of the WHO's mental health and development activities where they claim to be following a human rights approach. People in developing countries that do not currently have mental health legislation are asking whether they need to introduce such laws. Sometimes this is being asked in the context of the CRPD and whether these laws are necessary to help protect the rights of people with psychosocial disability. The reality in those countries with mental health legislation is that they are used not to protect the rights of people with psychosocial disability but, as in South Africa, to give legal sanction to depriving them of their most fundamental human rights.

The WHO documents correctly highlight stigma as a key issue — though it should be called by its correct name — discrimination, to make clear that it is community attitudes rather than any attribute of the stigmatised individual that is responsible. It also highlights examples of the ignorance, prejudices and fears that lie behind this discrimination, but fail to mention that the primary source of stigma in those countries that have mental health legislation is the legislation itself, which makes second class citizens of people with psychosocial disability. Further, they fail to examine the central role of the contested concept of 'mental illness' or to mention solid research showing that the neurobiological understanding of 'mental illness' actually increases rather than decreases the stigma/discrimination against people with psychosocial disability.[6] WHO is aware of this but chooses to remain silent.

Crazy Like Us is a recent book by American journalist, Ethan Watters, with the subtitle of *The Globalisation of the American Psyche.*[7] Watters looks at the emergence in recent years of four different psychiatric disorders in four different countries —– anorexia in Hong Kong, PTSD in Sri Lanka, schizophrenia in Zanzibar, and depression in Japan. In each case he found cultural narratives for these 'disorders' prior to the arrival of America's psychiatric diagnostic system. On every occasion he saw the American cultural narrative of biological psychiatry not only as damaging traditional, indigenous knowledge but also doing real harm to the individuals struggling with these difficulties. He was particularly surprised to see that the 'importation of Western diagnosis was not only changing the way patients and doctors talked about the disorder — it was changing the disease experience itself.'

The medical colonisation of psychosocial disability is virtually complete in countries like Australia and the US. The consequences are now surfacing and are not good. In *Anatomy of an Epidemic*, Rob Whitaker asks why the number of people in the US with long-term, chronic psychiatric disability has trebled during the period that was supposed to be a new era for the treatment of mental illness. The alarming conclusion is that the US mental health system, with its reliance on long-term use of psychiatric medications, is actually *causing* chronic and long-term disability.[8]

Conclusions

The WHO is at the vanguard of exporting a western, medical model of mental health to the developing world. It is doing this without presenting the heated debates in the west that this model often causes significant harm and seems to be actually causing long-term psychiatric disability. It is also failing to discuss the serious human rights issues that arise when western medical diagnoses are used to justify major infringements of the rights of people with psychosocial disability. Furthermore, the WHO's mental health human rights standards in their *Resource Book* are obsolete, given the existence of CRPD but there is no indication from WHO as to when these might be revised or replaced. When it comes to psychosocial disability, WHO seems to still be living in a pre-CRPD world. It is time they dragged themselves into the 21st century and paid attention to the CRPD and the social model of disability on which it is based. In its development activities, it needs to come clean, and disclose and discuss the many controversies in the model they are so enthusiastically exporting to the developing world.

Notes

[1] Available at: http://www.who.int/mental_health/policy/mhtargeting/en/index.html

[2] Quoted from WHO website — http://www.who.int/mental_health/policy/mhtargeting/en/index.html

[3] ICF stands for the International Classification of Functioning, Disability and Health, which is the WHO's model and definition of disability, see http://www.who.int/classifications/icf/en/

[4] One of many authoritative references that debunk the 'chemical imbalance' myth is *The Myth of the Chemical Cure* by Joanna Moncrieff (Palgrave Macmillan 2009).

[5] For an example from South Africa see WHO, 2010, Mental Health and Development, Box 14, p.49.

[6] A recent study that confirmed previous similar findings is "'A Disease Like Any Other'? A Decade of Change in Public Relations to Schizophrenia, Depression and Alcohol Dependence" by Pescosolido et al in the *American Journal of Psychiatry*, September 15, 2010 (doi: 10.1176/appi.ajp.2010.09121743).

[7] *Crazy Like Us — The Globalisation of the American Psyche*, Ethan Watters, Scribe, 2010

[8] *Anatomy of an Epidemic*, Robert Whitaker, Crown, 2010.

Eye health and the Millenium Development Goals: Progress in Asia and the Pacific

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Introduction

Blindness is a major cause of disability globally. Efforts to eliminate avoidable blindness have a central role to play in achieving the eight Millennium Development Goals (MDGs). This article provides an overview of the link between blindness and the MDGs and outlines the leadership role Australia has taken in addressing this link through the Avoidable Blindness Initiative (ABI).

Recent research suggests approximately 400 million people are blind or vision impaired from refractive error, eye diseases and other conditions[1] and that a further 517 million are short sighted and do not have spectacles.[2] Approximately 40 million people worldwide are completely blind. Ninety per cent of global blindness exists in developing countries with over half of all blindness in Asia and the Pacific. With today's knowledge and technology, 80 per cent of global blindness is preventable or treatable and programs to tackle avoidable blindness are among the most cost effective of available public health interventions.[3] Vision impairment has a huge impact on people's dignity and opportunities in their lives. Blindness stops children from receiving an education, prevents adults from working and contributing to their families and communities, impacts women more severely than men and causes widespread poverty.

Programs to improve eye health and reduce poverty

Programs to improve eye health can play a central role in achieving the MDGs and are among the most cost effective development activities. Studies have shown that blindness is both a cause and consequence of poverty and its prevalence is five times higher in poor countries.[4] Appallingly, blindness is fatal for many children. Up to 60 per cent of children in low income countries die within two years of becoming blind. Reducing blindness is therefore vital to reduce child mortality (MDG 4).

Approximately 90 per cent of vision impaired children in developing countries are deprived of schooling and blind adults often require full time care from school-aged children. Programs that aim to eliminate avoidable blindness will therefore assist in achieving the goal of universal education (MDG 2). Such programs also contribute directly to achieving gender equality and empowering women (MDG 3). Women are affected by blindness and vision impairment to a much greater extent than men — surveys indicate that women account for 64 per cent of global blindness, are less likely to be able to access care or have access to cataract services and girls are more likely to contract trachoma than boys.[5]

Political momentum

The past decade has seen a ground swell of global momentum towards the elimination of avoidable blindness. Governments, multilateral agencies, NGOs and other stakeholders are increasingly aware that, to achieve the MDGs, addressing the basic right of every person to maximise their ability to see is a good starting point.

In 1999 the World Health Organization and the International Agency for the Prevention of Blindness, recognising the central importance of good sight, launched the initiative known as VISION 2020: The Right to Sight. VISION 2020 captures and reflects the expertise of world class health professionals and provides a framework for national governments, health workers, NGOs, corporate bodies and donors to address the main causes of blindness and vision impairment.

At the political level, the VISION 2020 approach has resulted in 28 of 39 countries in Southeast Asia and the Western Pacific committing to VISION 2020, and over 100 countries worldwide implementing national eye care plans. One hundred and fifty countries have participated in a national VISION 2020 planning workshop, and 188 countries have established prevention of blindness committees.

World Health Assembly Resolutions were passed in 2003 and 2006 urging member states to build upon blindness prevention efforts nationally, regionally and internationally. In 2009, the World Health Assembly endorsed the Action Plan for the Prevention of Avoidable Blindness and Visual Impairment, consolidating this as a key international public health issue and placing further responsibility on governments around the world to act.

Australian leadership

Over the past decade, Australia has established itself as a global leader in efforts to eliminate avoidable blindness and reduce the impact of vision loss. Australian NGOs have a long history of tackling avoidable blindness all over the world, from its own remote Indigenous communities to Asia, the Pacific and Africa.

Vision 2020 Australia, as the peak body for the eye health and vision care sector, has led advocacy efforts to establish eye health as a priority in Australia's aid program. In September 2007 a delegation of Australian NGOs presented a ten year plan to both the government and opposition to eliminate avoidable blindness and vision impairment in our region which, if implemented, would eliminate avoidable blindness and reduce the impact of vision loss in Asia and the Pacific. In May 2008, drawing upon this regional plan, the Australian government announced that it would fund a three year $45 million Avoidable Blindness Initiative (ABI). The ABI seeks not only to eliminate avoidable blindness in Asia and the Pacific, but also to provide a range of low vision services to the 20 per cent of vision impaired people whose vision loss is not preventable or treatable.

Nine Vision 2020 Australia member organisations have formed a global consortium to ensure efficient programming of the ABI. The founding members of the global consortium are: CBM Australia, The Fred Hollows Foundation, International Centre for Eyecare Education, the Royal Australian and New Zealand College of Ophthalmologists, the Royal Australasian College of Surgeons, Centre for Eye Research Australia, the Royal Institute for Deaf and Blind Children, Foresight and Vision Australia. In 2009 the global consortium finalised a partnership framework with AusAID. In November 2009, the then Parliamentary Secretary for International Development Assistance, the Honourable Bob McMullan launched the Vision 2020 Australia Global Consortium. Agencies commenced implementation of the consortium's first workplan across Asia and the Pacific in early 2010 with activities in Vietnam, Cambodia, Fiji, Samoa, Timor-Leste, Solomon Islands and Papua New Guinea (PNG).

The Global Consortium's approach

Strengthening health systems is at the heart of activities undertaken by the ABI. Health workforce development is a crucial step in eliminating avoidable blindness. Training of eye health cadres is taking place and agencies are working with government and non-government partners to ensure that effective human resource development plans and systems are in place. Service delivery, including surgeries and establishment of hospitals and eye care centres, is having a strong impact and ensuring the sustainability of eye health programs, while the provision of spectacles and medicines is improving the health and quality of sight of thousands of people.

VISION 2020 and the Global Consortium are great examples of creating global partnerships for development (MDG 8). They are tangibly reducing the number of people who have a disability while increasing access of people with disability to development programs.

Disability mainstreaming

Aside from implementing programs that directly restore sight and build capacity of countries in Australia's region to tackle avoidable blindness in years to come, Global Consortium agencies are also leaders in disability inclusiveness. Strategies employed include:

- working in partnership with DPOs, such as the Cambodian Development Mission for Disability and the Association of Blind Cambodians,
- providing rehabilitation services;
- ensuring that eye care facilities are constructed in an inclusive manner, with access ramps, disabled toilets, for example;
- developing rural clinics and outreach services to enhance access to services by people with disability who are unable to travel due to physical or socio-economic restraints;
- proactively involving people with disability in project designs;
- including components on disability inclusiveness in training courses through tailored curriculum and teaching materials; and
- monitoring program outputs and outcomes for people with disability.

Summary and action needed

There has been dramatic progress in the global fight against avoidable blindness in recent years. Figures from WHO show that over the past five years the number of blind people globally fell from approximately 45 million to 40 million. This is five million more people who can receive an education, contribute to their families and communities, and live lives of independence and dignity.

Yet more is needed. It is essential that aid donors recognise the vital role eliminating avoidable blindness can play in their own strategies to achieve the MDGs. This applies not only to governments, but also to agencies like the World Bank, Asian Development Bank and African Development Bank. It is also essential that governments in developing countries match the efforts of international NGOs and aid donors and provide adequate levels of funding for their own eye health sectors, reducing poverty and ensuring that recent progress is built upon.

Notes

[1] AMD Alliance International and Access Economics 2010, 'The Global Economic Cost of Visual Impairment'.

[2] Holden B et al 2008, 'Global Vision Impairment due to uncorkrected Presbyopia', *Archives of Ophthalmology*, 126 (12): 1731.

[3] Marseille E 1996, 'Cost effectiveness of cataract surgery in a public health eye care program in Nepal', *Bulletin of the World Health Organization* 745, 319–324.

[4] Resnikoff S et al 2004, 'Global Data on Vision Impairment for the year 2002', *Bulletin of the World Health Organization* 82, 844–851.

[5] Courtright P and S Lewallen 2009, 'Gender and Eye Health', *Community Eye Health Journal* 22 (70).

Innovative approaches to social inclusion of people with disability

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Problem definition

Many people with disability face the pain of being socially excluded and isolated in both developed and developing societies. This paper presents an innovative approach to disability inclusive development using existing case studies from Australia. The aim is to increase social inclusion for people with disability in Australia, as a developed country, which can also be applied to developing communities.

Setting the scene

We set the following parameters. Because there is no uniform understanding of 'disability' in many societies around the world, developed or not, we first need to adopt a single definition and to set the framework for study. We adopt the social model of disability (SMD). This dates from 1960s and originates from the Disabled People's Civil/Human Rights movements. It addresses the deficiency of the medical model which identifies disability as being caused by external sources rather than from within the individual. External sources can be society's infrastructure not accommodating the diverse physical impairments of individuals, social attitudes, organisational and environmental conditions. Essentially, the SMD takes causes of 'disability' away from the individual and places it with the environment and the people around them (Oliver 1990).

As a consequence of adopting the SMD perspective we become aware of social and physical barriers that separate people in a community into two groups: people with disability (PWD) and people without (PW). Many people in the community have the perception that a PWD is someone who is not physically normal or uses a wheelchair. In a developed country such as Australia, this is constantly being reinforced, for example, by the use of symbols to designate 'special' areas, services or products for PWD. The symbol is usually a wheelchair logo or logos depicting sensory impairment.

Next, we recognise that many people in the PW group are involved in solving the problems of PWD and disability development. For the context and framework of this paper we will focus on people who are engineers, industrial designers or architects. This paper will present case studies on how engineering and industrial design are significant professions to formulate practical applications of the SMD.

The common ground bridge

We use the analogy of building a bridge between PWD and PW in order to create a more inclusive society. We visualise 'common ground' as the bridge between the two groups. This can come in many forms and is usually built on the social commonalities that each individual in a community shares with another. This 'common ground' can be said to be the social bonds that hold a group or community together. Five types of common ground and how they are applicable to disability development are discussed. These are the most applicable to this paper and are developed from personal experience as a person with disability, systems engineering research and social enterprise experience.

1. Common experiences

In our everyday conversations, we take for granted common experiences shared between our friends and families. We often make assumptions in social groups that the other person can understand our jokes based on out experience or agree on popular topics such as 'tagging' one's best photo on facebook or sympathising on how sore it can be after a snow trip. Imagine not having these common experiences due to lack of access to education materials, to websites and social media and not having experienced snow trips. It is the challenge that many people face regardless of disability, but is more pronounced when a person is unable to access the services and products in order to gain the common experience we take for granted in our social groups.

This is also the same for a PW who does not have the experiences of a PWD. For example, many people have not experienced using a wheelchair for daily activities or socialising without vision.

2. Common language

One of the main causes of social exclusion is a language barrier, something clearly seen in a country like Australia with diverse nationalities. Imagine being deaf or speech impaired. This causes severe disadvantage in accessing the common language we take for granted in social groups. And note that common language doesn't necessarily need to be the ability to speak the same tongue. It can be the way we use expressions or wording, presuming our peers know what we mean. We consider two examples in our language English:

> 'Let's go for a walk in the park'. A common expression most of us use yet we often neglect the 'walk' part, that is until we notice the person we are addressing cannot walk.
>
> 'Do you see what I mean?' This is another common expression and often people who are blind are aware of its use; it can yet create an awkward situation in a conversation.

These examples highlight the disconnection created between PWD and PW.

3. Common products

In many communities, there is a clear thirst for the latest trend, such as fashion or technological products. In Australia, iPhones are widely adopted as a trendy, must have, product. There is clear social acceptance of someone who has an iPod or iPhone; it is not only an adoption of trend but a demonstration of status. We can see that a trend-setting device can have the ability to create the social inclusion bridge to connect the worlds together. In developing countries, other products or devices can be used to build the bridge, for example, mobile phones. As they are now cheaper and more affordable, many people in developing countries have a mobile phone as their primary form of communication (Tryhorn 2009). We should then consider and adapt these devices for PWD for their social value, not just function.

4. Common friends and families

In Australia, almost one person in five people has a disability (ABS 2009), so most people know a PWD as a friend or family member. This is a notable common ground that should be used more often in community development campaigns. Also, this fact is not necessarily shared as something bragged about because we know that many people in developing countries see a person with disability as bad, someone to be ashamed of, particularly in families (JICP 2002).

With the right approach this common ground can help us realise that there is a significant number of PWD and share solutions with one another. Knowing someone who is 'elderly' is even more common than knowing someone with a disability yet many people do not see the close relationship between PWD and the elderly. The elderly use the services and products — wheelchairs, hearing aids, special glasses in the same way as PWD. Old age has an impact on mental, sensory and physical mobility yet many elderly people do not like to be thought of as disabled.

5. Common religion

In many developing countries, religion is one of the most significant social bonds. We should consider this as one of the most important bridges that needs to be built to enable social inclusion. Many religious venues lack physical access thus prohibiting many PWD from attending a place of worship. We should consider these venues not only as places of worship or prayer, but as providing an opportunity for friends and families to socialise. Organisations such as CBM have taken the initiative with their Luke 14 project, where they equip churches with the information and resources to include PWD (CBM 2010).

The common ground thinking should be seen as two-way exchanges, not only we need to develop common grounds in PW but we need to develop it in PWD for social inclusion to take place.

Role-play

Using role-play to educate and understand a problem is not new, yet in the context of disability, is not used often enough. This may be due to negative perceptions of disability in the past because role play with a person with disability would have been seen as a bad thing to do. Trying out a wheelchair by someone without the necessary disability may be considered ignorant and rude. Children being told they will acquire a disability by parents for playing with their friend's crutches, wheelchairs or other disability aids is another example of the same sentiment.

As disability becomes more part of the community's general awareness, role playing may become a positive learning experience. Role-play is an ideal way to build 'common experience' for PW.

Case Studies

We will look at four case studies that illustrate different aspects of how role-play can be applied to disability development. Two examples will examine how it may be used for problem solving in engineering and industrial design. The third example will show how it may increase empathy for social situations faced by PWD, adding to the common experience. The fourth example will analyse an existing use of role-play within an international development organisation.

Case Study 1: Engineering

In 2009, a role-play design experiment was conducted on graduate engineering students at the Australian National University (ANU) with the following questions in mind:

1. Does the incorporation of role-play improve the initial design?
2. Is it useful for a design process in regards to disability?

The participants were tasked with re-evaluating, and if they saw fit, redesigning a wheelchair for the user age group 18–25 using standard engineering design methods. They were provided with two ordinary wheelchairs to help analyse and understand the task. For the first part, they had limited time to develop a list of recommendations and ideas on how the chair could be improved. Participants then experienced what it is like to go shopping in a wheelchair and were then asked to evaluate their ideas based on the new experience.

Participants recognised the value of role-play. Each produced more subtle requirements after experience of using wheelchairs. Female participant 1 thought about the difficulty of using her hand bag while her arms were pushing the wheelchair. This was an observation regarding not only the functional requirement of the handbag but its social impact.

There were two other notable results of the experiment in regards to the experiences of the participants:

Result 1: Easier to address environment

In accessing doors, participants concluded that it would be easier to address the design of the doors than that of the wheelchair. This point demonstrates that the physical environment is a primary cause of a person's inaccessibility (disability), and was best described by the SMD.

Result 2: Personal reflection

> Participant 1: 'It can look a little obvious that you are "only role playing" if there are a group of you all together in the same type of wheel chair or when you don't have the upper body strength that someone who has been in a wheel chair for many years would have. You feel like you are deceiving people who are going out of their way to help you. This also makes you feel a bit scared about "getting discovered"' (Geeves, 2009).
>
> Participant 2: 'The biggest preventions to others using this method would be:
>
> - If the designer isn't extroverted then they will probably struggle.
> - A designer may feel that role playing a disabled person is deceptive to the shop attendants etc' (McIntosh, 2009).

These results highlight that subtle, yet important, design requirements are only identified when role-play is applied. There are challenges in applying this method as noted by the participants. However, if used more often, the mind set of engineers could be changed to see that role-playing in disability-related projects has benefits that outweigh the feeling of deception or awkwardness. This is especially important for technical disciplines such as engineering, as most technical solutions have a social impact on the lives of people, and should therefore be considered early in the design process.

There are already engineers in the automotive industry applying role-play in their design and evaluation process, for example, in the form of empathy suits to mimic the experiences of an elderly person (Edwardson 2008).

Case Study 2: Industrial Design

In February 2010, industrial design students at the University of Canberra made empathy suits to mimic particular conditions of aging with the following aims:

1. Expose and develop empathy in students to aspects of life experienced by others.
2. Introduce inclusive design and alternative nomenclatures.
3. Allow students to demonstrate understanding of the topic.
4. Develop group working skills.

They were given the following background to get them started:

> Designing objects and services for users can often involve designing for people you do not have a full understanding of or empathy for. The Macquarie Dictionary defines empathy as n. 'the entering into the feeling or spirit of another; appreciative perception or understanding'. This project provides the opportunity to learn about and experience some of the challenges other people have interacting with the everyday world around them (Trathen 2010).

There are clearly close correlations with the SMD. Interviews with two students elicited the following key points (Sibrava 2010, Stehlike 2010):

- The experience is valuable in the design process.
- They observed many other students needed to reconsider their designs, which focussed on themselves rather than on the user.
- They found that it was fun to do and could see the direct connection with projects related in disability.
- They gained an emotional perspective.
- They realised the value of empathy in understanding the problem.
- From their own experiences, both students perceived disability as a limitation of the person. However, when presented with the concept of the social SMD, they found that it was a better way of understanding disability and made more sense when attempting to address it.

These brief findings demonstrate the practicality of the empathy suits in design to help students understand the environment and context of problem. They are a valuable tool for gaining common experiences between the user and designer, promoting development of products that both PWD and PW can share.

Case Study 3: Social

This brings us to an example of role-play that is more focused on the social aspect of PWDs. In 2008 a disability awareness day was organised at the ANU for students to have fun and learn about the social challenges faced by a people who are blind. The event was blindfolded speed dating where participants were blindfolded and sat down on a 'casual' date with another participant who was also blindfolded. This demonstrated the difficulty of a typical social event if a person is blind. Issues faced by persons visionally impaired include the logistics of the environment, the material used by the venue which can reflect or absorb sound and most importantly, eye contact which is important in conversation. In relation to disability development, the environment can be improved to remove obstacles heavily dependent on vision.

This is an example of how disability awareness can be made into fun events that help remove the stigma associated with disability. Furthermore, it helps people develop the common experiences to understand the challenges of people who are blind.

Case Study 4: International Development Organisation

Finally, in the context of international development, particularly in disability development, there exist ways we can adapt to disability. As part of Engineers Without Borders (EWB) education programs, EWB has included the monsoon game into their curriculum. 'Delegates act as an Indian farming family and explore issues of poverty and justice under the fickle Indian monsoon. The monsoon game is a realistic and highly interactive simulation game that focuses on some of the dynamics of poverty in an imaginary village near Mysore in India. Players take the roles of farmers and experience some of the forces that shape people's lives in a village' (TEAR 2009).

This kind of established activity proves role-play can be successful in organisational development. It provides a platform for role-playing activities to be adapted to help educate staff and members in the organisation and increase their understanding of different disability types.

Conclusion

We know that many PWD are socially excluded and isolated. It can be difficult to understand the causes of these problems, because disability as a development theme is diverse and cuts across all sectors. To address this diverse issue this paper adopts one definition of disability, the SMD. The result of adopting this model helps shift the focus of disability away from the person to the social and physical barriers around them. With this shift in thinking this paper presented the concept of common grounds to bridge the barriers between PWD and PW. Role-play was then presented as practical tool that can be used to develop some of the types of common ground to ultimately work towards the goal of social inclusion for PWD and PW.

References

ABS 2009, *Statistics of Disability, 5* June 2009, http://www.abs.gov.au/, accessed August 2009.

CBM 2010, *Christian Blind Mission — Luke 14*, 29 August 2010, http://www.cbm.org.au/content.aspx?id=219, accessed August 2010.

Edwardson, Grant 2008, — http://www.worldcarfans.com/10802252127/nissan-engineers-use-special-suit-to-simulate-the-elderly, accessed August 2009.

EWB 2009, *Pathways 2 Development,* Canberra, 15 August 2009.

Geeves, Aleena 2009, *Feedback from role-play wheelchair design experiment*, Graduate Engineer, Australian National University, interview by Huy Nguyen, 10 September 2009.

JICP 2002, *Country Profile on Disability: Cambodia, Vietnam*, Japan International Cooperation Agency Planning and Evaluation Department, 2002.

McIntosh, Lawrence 2009, *Feedback from role-play wheelchair design experiment*, Graduate Engineer, Australian National University, interview by Huy Nguyen, 10 September 2009.

Oliver, Mike 1990, *The Individual and Social Models of Disability*, 23 July 1990.

Sibrava, Aiden 2010, *Experiences with empathy suits,* Industrial design student, Faculty of Arts and Design, University of Canberra, interviewed by Huy Nguyen, 5 August 2010.

Stehlik, Hugh 2010, *Experiences with empathy suits,* Industrial design student, Faculty of Arts and Design, University of Canberra, interviewed by Huy Nguyen, 29 June 2010.

TEAR 2009, *TEARAUSTRALIA — Monsoon*, 2009, http://www.tear.org.au/resources/items/monsoon/, accessed September 2009.

Trathen, Stephen 2010, *Course in Industrial Design – Empathy Suits*, Senior Lecturer Industrial Design, Faculty of Arts and Design, University of Canberra, interviewed by Huy Nguyen, 8 June 2010.

Tryhorn, Chris 2009, *Developing countries drive explosion in global mobile phone use. 2 March 2009,* http://www.guardian.co.uk/ business/2009/mar/02/mobile-phone-internet-developing-world, accessed 29 August 2010).

Note

[1] The editors of this paper were Jeremy Smith, College of Engineering and Computer Science, Australian National University and Rohan Mitchell, Gr8venue.

Developing a National Disability Policy: The Timor-Leste experience

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The fourth Constitutional Government of Timor-Leste has as a national strategic priority the development of a policy that embraces people with disability and strives for quality and excellence in their integration as well as access to service provision. Enabling acceptance and inclusion of people with disability will enhance the social, economic and cultural development of the country.

The National Disability Policy will be the cornerstone of all disability service provision, which is required by the Constitution to be universal, mandatory, inclusive and accessible. It was initiated and supported by the Ministry of Social Solidarity [MSS] in partnership and co-operation with people with disability, the community and other Ministries and relevant agencies.

The policy aims to establish a sustainable 10 year vision for people with disability in Timor-Leste, with various achievable short term policy principles. The policy principles have been developed from the key eight principles articulated in the CRPD. Other significant principles were added by *Ra'es Hadomi Timor Oan* (RHTO) — the National Disabled People's Organisation (DPO). All principles are in harmony with the Constitution of Timor-Leste and will allow the community the opportunity to develop an inclusive Timor-Leste. More than 300 people with disability, their families and communities participated in the development of the policy. Other significant stakeholders, relevant ministries and disability agencies were also interviewed and their views recorded.

Country background

High levels of conflict in Timor-Leste's history prior to independence in 2002 have left the country of 1.1 million people with a higher than usual proportion of people with physical and psychosocial disability and a very high proportion of people living in poverty. Since the country's independence was restored there has been government and non government organisation recognition of the need for policies and practical support for those with disability. Although a disability survey and national census conducted in 2002 identified only two per cent of the population with a disability, the reality was very different and it is estimated that at least 15 per cent of households are affected by disability. It may be even higher as so many people suffered physically and mentally during conflict prior to and after independence. Many still suffer trauma.

The official languages in Timor-Leste are Tatum, which is a local language, and Portuguese. The working languages are English and Bahasa. Sometimes we use four languages in the same situation. This can make developing policies and other national documents difficult.

Disability inclusive activities

Initially, disability service provision was led by national NGOs but the government is now committed to supporting disability-inclusive services. The Ministry of Social Solidarity provides community-based rehabilitation programs and is improving access for the poor and people with disability to education and training. In 2008, in partnership with NGOs, the vocational training and employment sectors have organised training for members of DPOs to do vocational training in carpentry and at the present time, they are facilitating the development of an infrastructure for the members of this organisation to start a business project.

The Government has subsidy schemes for people with disability who are over 17 years old and also for the elderly. This is a monthly payment provided by the Government as well as scholarships for children with disability who are under 17 years old, and also for families with more than five children with a priority given to female-headed households.

We have also have strong networking and advocacy of for disability-inclusion through the disability working group, where local NGOs, national NGOs, government ministries, donors and the United Nations agencies come together to share ideas and information and to advocate among government for the rights of people with disability.

But there remains a dearth of services for people with disability in Timor-Leste and many agencies are inexperienced in the delivery of quality services. They need policies to guide them. It is a challenge to ensure that people with disability become more visible. All agencies will need to work to eradicate stigma and promote participation of people with disability. It is essential that existing services and agencies share information, education and training resources. Advocacy services must be properly recognised and funded and the whole of government must work together to ensure inclusion of people with disability.

Developing a National Disability Policy

As we knew we should have proper standards for socially inclusive services we started to develop a National Disability Policy in 2006. We currently have three documents: the National Community-based Rehabilitation (CBR) strategy, a CBR training framework, and a draft National Disability Policy. The purpose of the National Disability Policy is to introduce a rights-based approach and to ensure that all citizens of Timor-Leste who have a disability are able to access services in full and can enjoy the whole of their human rights and fundamental freedom and also be given the respect for their inherent dignity. This policy is aimed to facilitate a whole of government approach to service provision and also the full participation of people with disability in all aspects of life.

Developing the National Disability Policy has been a long and difficult process, due in part to definitions, political upheaval, changes in approach, using different overseas advisers, communication difficulties and to the difficulties in Timor-Leste of working in four different languages — Tetum, Bahasa, Portugese and English. Communication has been the main barrier to finalising the policy. It is written in English, then has to be translated into another language for national consultation with stakeholders and if it goes to the government it has to be translated into Portuguese, because all official documents have to be translated into the Portuguese language. As not many young people speak Portuguese this makes it a bit difficult. Another problem has been the doubling up of the work as different advisers have different styles of working, different translators, different approaches.

A draft was developed in 2006 by an international adviser who undertook consultation with the different stakeholders and people with disability. It could not be finalised due to the crisis in 2006. A second draft in 2008 was developed by an international adviser from New Zealand, who had experience of disability policies in the Pacific region. The draft was not finalised as there were difficulties within the Ministry in providing adequate support for the adviser. Then, assistance was provided to expand and complete a third draft. Extensive work was carried out in terms of consultation with people with disability, and in Dili, all ministries, communities, as well as people with disability, throughout the organisation were consulted. It was completed in 2010 and presented to the Council of Ministers for approval. It was returned to the Ministry of Social Solidarity for revision and the inclusion of a monetary strategy and action plans. A national adviser, funded directly by the Ministry, was appointed by the Minister to complete the policy.

What we experience within the Ministry, especially after the crisis where we must deal with so many internally displaced people, is a shortage of human resources – they are not sufficient to support the international advisers undertaking their tasks. With the current policy draft, there are not enough government points of view reflected in it. So the next step now is to review the current draft and finalise the policy to be re-submitted to the Council of Ministers in November of 2010. To strengthen the role of disability working groups in Timor-Leste the disability working group has a major role to play in terms of monitoring the implementation.

Some of the positive outcomes of the work on the policy are related to the development of the national organisations in Timor-Leste. After so much consultation we now have a strong movement, including the work done by the DPOs in Timor-Leste.

Next steps

We need to strengthen the capacity within the Ministry itself as our human resources are so limited. The current institutional support that is provided by the Ministry needs to be strengthened particularly in terms of monitoring the agencies it funds. Also, the national CPR strategies that were launched recently by the Minister require additional human resources to be able to monitor implementation.

We still have a long way to go, but I think in terms of the disability work in Timor-Leste, we are heading in the right direction.

Implementing disability-inclusive development

Megan McCoy, Regional Specialist, Disability Inclusive Development, (Asia) AusAID

I would like to summarise what is happening in terms of global, regional and national disability frameworks and then to pose questions about implementation; because that is, after all, the focus of this journal.

We talk a lot about national frameworks, and what they mean, but I would like to draw attention to the importance of having a national policy on disability. Quite simply, without a policy it is impossible to get budget for implementation. Without community, provincial and national policies and strategies I do not believe we will have effective action on disability. For the most part, global and regional frameworks need to be translated and adapted to meet the individual context of each country.

Regional frameworks can have some very important uses. When the Pacific Regional Strategy on Disability was being developed my colleagues were somewhat strategy weary and asked 'What is the point of having another regional strategy?' I replied, 'Well, small countries in the Pacific will need to pool resources in order to bring together government and civil society stakeholders for national action. With disability, a regional strategy represents the most sensible and efficient approach.'

In the Asian region, ASEAN can provide an important framework for disability in terms of sharing lessons learned within the region. What we are trying to do in disability inclusive development is not rocket science; what a neighbouring country has done could well provide useful lessons for you.

Looking inwards and outwards

In disability, there are those of us who look inwards to our own communities and countries to improve the lives for people with disabilities. There are also people like myself who look outwards, we work for bilateral donor agencies, international development NGOs or international disabled persons organisations.

This is where global frameworks need to be considered, the most important of which is the Convention on the Rights of Persons with Disabilities. Article 32 of the CRPD concerns international cooperation. The Convention means that those developed countries that have signed and ratified are committed to ensuring their development assistance includes and benefits people with disabilities. The Convention can also provide a normative basis for action at the national level. It sounds theoretical, but that it is in fact a practical example of the value of conventions.

The importance of asking questions

With regards to implementation, and what we do next, from my perspective it is important to ask questions.

There are some really positive examples. I've learned that the AusAID Philippines program is doing a situational analysis on disability. For me, that starts from a very simple basis. What do we need to know and what do we need to do? Asking questions like through a situational analysis is a powerful starting point. It provides good information for strategic action.

We had a recent AusAID Disability Reference Group meeting in Cambodia. We heard from the AusAID Cambodia team about the things that they were already doing to make sure that their mainstream development programs were inclusive of people with disabilities. Like the Philippines example, this process all starts from a question. A really positive example was the rural livelihoods program where AusAID asked the implementing partner, 'Can you please provide a strategy on disability and gender?' And they got one. There is a long way to go, but it's a starting point. All it took was one person asking one partner one question. And to me that's implementation.

AusAID recently completed a survey of staff on their attitudes to disability. The survey will help make sure capacity building on disability-inclusive development meets the needs of those staff. This was asking also about questions to help support good practice implementation.

I also asked questions during my work at the New Zealand aid program. We had some internal presentations about gender and disability mainstreaming where I talked about our commitments to disability in the aid program. After my presentation I asked the question: 'So knowing what we know now, what should we do to implement our commitments?' Unfortunately there weren't many answers. However, there was a positive effect as two colleagues went on to participate in a disability and development workshop with the Council for International Development in Wellington (the Australian ACFID equivalent).

This process is just about asking questions. It started with me asking a few questions and finished with some colleagues going an asking other people questions. It is as simple as that.

The good thing about asking questions is that eventually, hopefully, you will start to get the right answers. A few years ago I had my own questions on disability and development so I asked around 'who do I talk to if I want to know more about including people with disability in my program. The answer was, go and speak to the health adviser'. At the time I thought, well, that's not quite right, this isn't a health issue it's a human rights issue.

Earlier this year, when we were preparing our baseline report on the CRPD, specifically Article 32, I presented some information to our senior management team. I asked a question 'We have some gaps in our practice, and we need to do something about it. Who should be responsible for leading this work?' I was really pleased when the answer came back 'well, what we should do is look to incorporate this into our human rights work'.

So for me, asking a question is a catalytic process. It all started with a question at my former agency, and eventually, over time, the New Zealand aid program saw that disability was not a health issue, but first and foremost a human rights issue. So, in terms of implementation the message I'd like to leave you with is — just ask a question. We have global, regional and national frameworks in place. Implementation will depend on individuals asking questions about what happens next. And eventually, we will start to get the answers we need.

What makes an effective partnership: The experience of a global fund

Diana Samarasan, Director, Disability Rights Fund

I would like to explore the mechanics of partnership within the context of the Disability Rights Fund. This paper is in three parts. First, some context for the development of the Disability Rights Fund and its history. Next, the structure of the fund and our funding strategy and finally, lessons from our grant making. In many ways the development of the Disability Rights Fund parallels the progress of the CRPD.

The idea of the Fund was born between philanthropic advisors and disability activists who were attending the ad hoc meetings leading up to the adoption of the Convention. They saw a window of opportunity in the paradigm shift brought about by the Convention to address disability within philanthropic and human rights rather than a charity issue. To give a sense of where this began — only 40 of 191 UN member states have any disability legislation. If the US is any measure, only four per cent of philanthropic foundation funding in the US goes to disability and the majority of that is given from a charity versus an empowerment perspective.

In 2007, an anonymous donor invested money to hire a consultant, who was me, to liaise between the global disability community and donors and grant makers to build a structure for a pooled fund made up of multiple donors. In the world of philanthropy, this investment in a process of dialogue was a novel idea. It built on the new grant making philosophy of involving granting communities in the development of grant making strategies. But it seemed to make sense that you could not have a fund that aimed to operationalise the Convention on the participatory principles of the rights of people with disability without also incorporating that principle in the structure of the fund itself.

Disability Rights Fund structure

The Disability Rights Fund empowers disabled persons organisations in the global south and Eastern Europe to advance the rights of people with disability at country levels utilising the Convention. The structure and funding of the Disability Rights Fund dialogue, which was begun in 2007, lasted almost a year and resulted in a framework document which detailed the mission, scope, governance structure and intended grantees of the Disability Rights Fund which are Disabled Persons Organisations (DPOs). The framework was vetted by both the grant making community and the global disability community as represented by the directors of the International Disability Alliance membership organisations and regional DPO networks.

The structure outlined includes a global advisory panel of 12 members, 11 of whom are people with disability from the global south and Eastern Europe. The majority of advisors were nominated by the International Disability Alliance membership organisations and regional DPO networks. The advisory panel meets once a year to recommend grant making strategy for the Fund, and they're now moving more towards their role in monitoring and evaluation as well.

There is a steering committee composed of four of those advisors chosen by consensus from among the global advisory panel and donor representatives. We started with three donors to the Fund. We now have seven and of the seven donors five have chosen to put a representative on to the steering committee. So the steering committee comprises four advisors and five donor representatives.

Fund donors

The donors to the Fund are very diverse. We have government donors, private foundation donors, public charity donors, donors who give us small amounts over a one year period, donors who give us larger amounts over multiple years and donors with varying emphasies. One of the donors came on board last year with resources for supporting DPOs in the Pacific Island countries as well as across the global south and Eastern Europe.

The steering committee operates by consensus. It meets twice a year and has oversight of the operations and strategy of the Fund. It finalises grant making guidelines and makes decisions about grants.

Fund staffing

In 2008, there was only one staff person and that was me. Now there are six staff of whom four are people with disability. This means that at every level of the fund — advisor level, governance level and staffing level, the Fund is attempting to meet the participatory principles of the CRPD. It is a unique collaboration or partnership between disability activists and donors and between donors themselves as they work together on the steering committee.

The grant making process

In July 2008 DRF announced its first request for proposals which went out to a pilot five countries — Ghana, Namibia, Bangladesh, Nicaragua and Peru. By the end of 2008 we had given out 800,000 dollars in one year of grants for awareness raising action on the Convention and network building to 33 DPOs in the seven countries. Since then we have held three more grant making rounds and have opened grant making to 18 additional countries — 14 of which are the Pacific Island countries. In total thus far we have fielded 634 applications and we've made 148 small to modest CRPD-represented advocacy grants to 159 different DPOs in 15 countries for grants totalling more than $3.4 million.

Within each grant making round we have two funding streams. We have a small grants funding stream which are grants from $5,000 dollars to $20,000 and last for a year. The majority of our grants are small grants. We have a national coalition funding stream which are grants from $30,000 to $60,000 over a two year period. These are grants which enable DPOs to increase their activities in addressing the Convention, to enhance their participation in decision-making processes regarding the Convention at state or local levels. This is especially important in those places where decision making is decentralised to district or provincial levels. The small grants also allow DPOs to directly address implementation of CRPD articles.

Some examples

For example, we target many of our small grants to especially marginalised sectors of the disability community and to emergent DPOs and new DPOs. For example, the Little People of Uganda was formed in 2008 and we gave them their first grant ever that year. It was only $5,000 to hold their first membership meeting and to learn about the Convention and to build a strategic plan about how they would address the human rights of Little People within Uganda. The grant had some additional positive outcomes that we weren't expecting. Through the grant, the Little People gained a lot of national media attention in Uganda, and through that they also gained political attention. They were invited to the Ministry that oversees disability issues in Uganda to talk about how Little People have been discriminated against even within the disability community. The disability community, in turn, opened their doors to this marginalised sector of the community. They also achieved a second and then a third grant, not only from us but from another donor.

On the national coalition funding stream side, we give these grants to three or more organisation that are working in partnership. This can be three DPOs working together at the national level, but it could also include other civil society organisations as long as a DPO is in the lead. These grants are given to support CRPD ratification efforts, advocacy for legislation which accords with the Convention and to support DPO reporting and monitor mechanisms.

Another example is from Ghana. Their Disability National National Coalition is made up of the Ghana Federation for Disability, which is the national umbrella organisation, Mind Freedom Ghana, which is a group of people with psychosocial disability and an organisation of journalists addressing disability issues. The grant is for a ratification campaign.

Selecting grantees

So at all stages of our grant making, from the review of proposals to the rest of the grants cycle, we provide technical support and aid. In the proposal review, we're not a strict donor. We don't throw out proposals that don't come to us completely perfect. We look for good ideas, and then we enter into a long process of dialogue with those applicants to get missing documents, to clarify what DPOs are intending to do. We also visit every one of our grantees at least once or twice a year. And we bring trainers in on the CRPD.

Supporting partnerships

A lesson I want to share is that again as in any community that is resource poor, there's a lot of in fighting between groups, whether that's between impairment groups or between national groups and local groups, and also mostly because of stigma and discrimination there's a lack of partnership between DPOs and other civil society or other entities. So we open a way for a partnership to increase the depth of the disability movement in every one of our target countries and to make the voice of a joint disability movement stronger. We do this by emphasising grants for partnership efforts, both at the small grants and the national coalition level, and at the outset of the grant making years in each of our countries, we hold grantees convenings. These convenings bring all of our grantees in any one country together to talk to each other, to talk to us, to reduce redundancy that might happen between grants, to build collaborations between organisations and to open path ways for advocacy to key stake holders. So we invite the grantee to convenings, not only the grantee partners but also key stake holders in the country for instance national human rights institutions, representatives, office of high commission nor human rights local representatives, government representatives, etc.

We also seek to influence every grantee to think about who they may be excluding. We do this by reviewing the constitutions and by-laws of grantees. We've found that as we've done reviews of many, many constitutions and by-laws that a large number of them have exclusionary clauses. For example, many constitutions and by-laws exclude people of 'unsound mind' from participation. We point this out and ask that the grantee organisations change their constitutions and by-laws to address these exclusions. I suppose the last lesson that I want to leave you with is simply that people with disability and DPOs are the best leaders for change. The risk is worth it and we feel this way at all levels of the Fund. We've learned this not only from the staff perspective but also all of the donors sitting around our table have invested in the risk of supporting the grass roots and national DPOs.

Partnerships with the Australian Government volunteer programs: Lessons learned

Marijke Fotia, Partnerships Coordinator,
Austraining International

Introduction

Australian organisations supporting disability inclusive development in Asia, the Pacific and Africa can utilise the Australian Government's international development volunteering programs to maximise development outcomes. The Australian Youth Ambassadors for Development (AYAD) and Volunteering for International Development from Australia (VIDA) programs are two Australian Government volunteering programs funded by AusAID that support skilled Australians to live, work and make a difference in Asia, the Pacific and Africa. The AYAD and VIDA programs partner with Australian organisations to develop and support volunteer assignments.

By using case studies, this paper will discuss how organisations supported by the Partnerships Team at Austraining International can establish and strengthen partnerships with international organisations through Australian Government volunteering programs and outline some development outcomes achieved by Australians working on disability assignments in Asia, the Pacific and Africa.

Austraining International

Austraining International is an international development and project management organisation focused on social development and the impact of its projects on the developing world. Through its significant experience on long term projects Austraining's core areas of business are managing volunteers, scholarships and technical assistance programs. Austraining is based in South Australia with a network of in-country and regional managers located in 20 countries across the region.

Austraining has more than 10 years experience in volunteering and has managed more than 3000 volunteers in projects across Asia, the Pacific and Africa, as well as a number of scholarship and technical assistance programs. Austraining currently manages AYAD and VIDA.

Volunteering for international development

VIDA places skilled Australian citizens and residents aged 18 and over on volunteer assignments in Asia and the Pacific, working with local people to share knowledge, develop sustainable skills and build capacity of individuals, organisations and communities in line with partner and Australian Government development priorities and the Millennium Development Goals (MDGs). VIDA assignments are from one to 36 months in duration.

Countries supported by AYAD and VIDA volunteers

Bangladesh	Mongolia
Cambodia	Nepal
China*	Papua New Guinea
East Timor	Philippines
Fiji	Samoa
Ghana*	Solomon Islands
Indonesia	Thailand
Kenya*	Tonga
Kiribati	Tuvalu^
Laos	Vanuatu
Maldives^	Vietnam

* Only AYAD
^ Only VIDA

Partnerships in disability

A main feature of the AYAD and VIDA programs is the involvement of Australian Partner Organisations (APOs). These programs provide the opportunity for Australian organisations to strengthen relationships with organisations in developing countries in Asia, the Pacific and Africa and to create new long term, sustainable partnerships. Approximately 30 per cent of all AYAD and VIDA assignments have an Australian Partner Organisation. These APOs can be any Australian organisation with an interest in international development — universities, government departments, NGOs and community-based organisations.

In the disability sector, programs have partnered with the following organisations: Arts Access Australia, Baptist World Aid, CBM Australia–Nossal Partnership, Interplast Australia and NZ, Royal Institute of Deaf and Blind Children, University of Newcastle, University of Melbourne, and Women with Disabilities Australia.

Volunteering and disability

Disability is a priority for AusAID and in a number of countries AYAD and VIDA have volunteer assignments underway. Since AYAD and VIDA programs began over 150 volunteers have worked on disability assignments, including volunteers with disability. The following two case studies look at volunteers from each program where an Australian organisation has used the volunteering program to build the capacity of their overseas partner organisation.

Case Study One

Briana Wilson, Occupational Therapist, Protibondhi Community Centre, Baptist World Aid

Briana is an occupational therapist who went to Protibondhi Community Centre (PCC) in Mymensingh, Bangladesh, where she worked with the PCC's community-based rehabilitation team. The team aims to network with local people with disability, optimise their abilities and work for social change through self-help groups, education, therapy and advocacy. PCC's community-based rehabilitation project for people with disability is funded by Baptist World Aid, one of AYAD's program partner organisations.

The partners

Baptist World Aid Australia works with local Christian partners overseas to serve those living in poverty. Their focus is to work through community development initiatives to help families access the skills and resources they need to improve their own situation. Through a variety of activities suited to each region, their partners (including PCC) seek to help children, women and men lift themselves out of poverty and become self-reliant.

The community development projects implemented by Baptist World Aid Australia's partners in Bangladesh seek to meet the needs of the individual communities which they serve. A key component to all projects is involving local people in the design and delivery of project activities, allowing for great variation between the activities and goals of different projects. A holistic and sustainable approach is fundamental to all projects — to combat the causes of poverty, empower communities to be agents of change and deliver tangible improvements for people living in poverty. Projects generally focus on issues like increasing family incomes, ensuring the community has access to safe water and adequate sanitation, improving nutrition and good health practices among families and building literacy, numeracy and small business skills.

The volunteer

Briana worked with local staff to increase their basic technical knowledge by facilitating their occupational therapy (OT) skills and supporting them in the field in the application of their OT knowledge and skills acquired through training. Using local resources, Briana developed and created samples of appropriate and simple assistive devices for people with disability and a directory of appropriate rehabilitation organisations for relevant support and resource links.

Lessons learned

Baptist World Aid found Briana's placement invaluable as they have a strong focus on capacity-building and were finding it difficult to provide appropriate support for PCC when visiting only twice a year. Having a volunteer based within PCC improved community-based rehabilitation services and provided a strong link between the two organisations which has led to planning for the future. Briana was able to provide useful feedback on how PCC was relating to the parent organisation in Bangladesh and give a better picture of the real capacity-building needs. Briana was able to balance the transference of skills to staff without actually doing their work for them. She enabled staff to feel empowered by the work of PCC.

A comprehensive briefing prior to placement of the volunteer in country was important to the success of this assignment. This preparation was expanded with the second volunteer who has recently gone to increase the volunteer's awareness of capacity-building and development. Briana has gone on to work with another organisation in Bangladesh.

Case Study Two

Ben Clare, Inclusive Education Officer, SENESE School, Royal Institute of Deaf and Blind Children.

Ben Clare is an Inclusive Education Officer working in Samoa who is now on his second VIDA assignment. His first assignment was in the Solomon Islands where he worked as a training officer. His current assignment is in Samoa working at the SENESE School as an inclusive education officer. Inclusive education is a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion from education and from within education (UNESCO 2009). Ben's assignment is supported by the Royal Institute of Deaf and Blind Children (RIDBC). Ben is blind and thought he would be unable to go on one of these assignments — he is now on his second and achieving remarkable outcomes.

The partners

SENESE is a school which was formed by a group of parents of children with special needs and has recently started supporting blind and vision impaired students. In partnership with RIDBC and the Australian volunteer, a well-resourced and effective vision support program is being implemented. This program is aimed at blind and vision impaired children attending regular schools throughout Samoa and is built on the inclusive education model. RIDBC work closely with SENESE and the Australian volunteer to provide equipment, training and other support services to ensure all children who are blind and vision impaired receive adequate and effective support in the classroom. This partnership is vital to the operation of SENESE and the volunteer is able to provide ongoing support on the ground in Samoa.

The volunteer

Ben has been in Samoa for about seven months and has already achieved a substantial number of desired outcomes. He has started an intensive Braille training program, involving several school teachers, students and SENESE staff. Through Austraining International's partnership with the RIDBC and funding from AusAID, Ben has been able to purchase expensive equipment including Perkins Braille machines and two Mountbatten Electronic Braillers which are being used in the schools and for training purposes. Ben has adapted to make Brailler accessible to Samoan speakers by changing the language to Spanish which has the same vowel sounds as Samoan. Therefore, when the Braille is input, it is read back in their own language.

In the coming months SENESE will be purchasing a full Braille transcription centre including laptop computers, an embosser and Braille translation software which will allow for mass production of Braille books for all Samoan schools where blind students attend. Ben will be training SENESE staff in the use of this equipment to ensure production continues after his placement.

Lessons learned

RIDBC have seen many benefits of the partnership with SENESE and the skill set of the volunteer. Ben is seen as a valuable asset to both SENESE school and RIDBC. Their collaboration is strengthening the relationship. Staff at SENESE are seen to be acquiring skills and resources through Ben including planning and working together.

RIDBC's advice for working in the future with volunteers is to prepare the volunteer well before they leave with all available information and advise the volunteer of the skills required and tasks to be performed. SENESE was also briefed regarding the volunteer's needs and realistic expectations of the volunteer and what he would be able to achieve on assignment.

Conclusion

In both these case studies the volunteers have been a valuable resource for the Australian and overseas organisations. They have been an extra link between Australia and the host countries and helped to strengthen relationships between the Australian Partner Organisation and host organisations. In both cases the Australian partner played an important role in briefing the volunteers before they were in country and also briefed the host organisation in the volunteer's skills and experience and the type of work the volunteer was able to do.

Partnering with the Australian Government volunteer programs can give Australian organisations the opportunity to strengthen their relationship with their partner organisations in developing countries. It can also provide a valuable human resource to assist with the work of your organisation.

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- Ms Birgit Cullen, Project Officer, Bangladesh, Formerly of Baptist World Aid Australia.

References

AusAID, Volunteering Overseas, http://www.ausaid.gov.au/partner/volunteer.cfm, accessed 25 October 2010.

UNESCO 2009, *Policy Guidelines on Inclusion in Education,* UNESCO, Paris, http://unesdoc.unesco.org/images/0017/001778/177849e.pdf.

Challenges, opportunities and the achievement of disability rights in Asia Pacific and Indonesia

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Rights and development in Asia and Pacific

Although disability rights and development approaches have been accepted widely in Asia and Pacific, the condition of people with disability in this region has not improved very much. The major challenges are:

1. The definition of disability and the concept of disability rights vary between countries. Disability rights in some countries focus on enacting and enforcing social services provisions for persons with disabilities which are actually part of welfare laws.
2. The implementation of equal opportunity and rights of people with disability in some countries is not clear. Some countries have accessibility provisions and apply a quota system.
3. Some countries have no mechanisms for coordinating disability-inclusive activities.
4. Few countries are equipped to monitor and evaluate disability policies and programs.
5. Lack of financial resources, technical skills and capacity in related disability issues.[1]
6. Self help organisations of people with disability have had important negotiating roles in enacting disability laws but most are focused on campaigns to raise awareness.
7. Program sustainability is often focused on individual figures and depend on donor agency funds.

Implementing disability rights: Lessons from and achievements in Indonesia

The Ministry of Social Affairs is the focal point for disability in Indonesia. It adopts a twin track approach developing disability specific programs as well as incorporating disability into mainstream development. The Ministry of Social Affairs has three main programs: social rehabilitation, social assistance and social security. The social rehabilitation program has three types of programs: institutional based, non-institution based and outreach programs. The Community Based Rehabilitation (CBR) programs are non institution based and outreach. By 2010, CBR programs have been developed in 16 provinces as national programs. Social security programs provide cash transfer for those who have very severe disability and live in poor conditions. By 2010 social security programs reached 17,300 beneficiaries in 32 provinces (Ministry of Social Affairs Republic Indonesia 2010).

Indonesia also passed the National Plans of Action (NPA) on disability 2004–2013. The NPA consist of eight priority programs:

1. Establishment of a self help organisation of people with disability and a parent/family association of children with disability.
8. Empowerment of women with disability.
9. Early intervention and detection of disability and education for people with disability programs.
10. Employment and job placement for people with disability.
11. Accessibility in public facilities and transportation for people with disability.
12. Accessibility in communication information technology, including assistive devices.
13. Poverty reduction through strengthening social security and sustainable livelihood programs.
14. International cooperation and human rights.

To incorporate disability into development, the Ministry of Social Affairs has initiated a National Coordinating Body for Disability Issues, consisting of government, NGOs, the Chamber of Commerce and academics. The National Plans of Action for People with Disability 2004–2013 was created by this body.

Achievements of disability rights have been made, in particular, in the area of legislation. Since 1997 the country has enacted Law No. 4 on Disabled Persons. Article (5) states that every individual with disability has equal rights and opportunities in all aspect of life.[2] This Law is equipped by Government Regulation No. 43/1998 on the Promotion of Welfare of Persons with Disabilities. A Presidential Decree No. 83 (1999) established a Coordinating Agency in Social Welfare Efforts for the Welfare of Persons with Disabilities which covers the role and function of the agency, its structure and memberships, establishment of working groups, working procedures and establishment of the Agency at the provincial and district levels.

Other progress relates to accessibility of public facilities and buildings, women with disability and health. Indonesia passed Law No. 28/2008 which provides for accessible buildings for people with disability and enables implementation through the Public Work Decree No. 468/KPTS/1998 on Technical Provisions for Accessibility in Public Buildings and their surroundings. By 2009, there were 255 accessible public buildings in Indonesia each provided with ramps, handrails, elevators, toilets, parking area and guiding blocks.

Indonesia considers that a rights-based approach is imperative in the context of development strategies. In May 2009, the government issued the National Strategy on Access to Justice. Access to justice is defined as circumstances and processes where the state ensures the fulfillment of basic rights based on the 1945 Constitution and the Universal Declaration on Human Rights. The strategy guarantees the right of every citizen to full information on his or her basic rights, in such a way as to gain an understanding of these rights and of the means to claim and enjoy them at all times and without restriction. One of the manifestations of the strategy is the Presidential Decree No. 3/2010 on Equitable Development, which reflects the government's policy to undertake just development, pro-people programs, focusing on providing justice for all and the pursuit of the Millennium Development Goals. This binds the responsibility of the local governments.

Indonesia signed the Convention on the Rights of Persons with Disabilities on March 2007. An inter-ministerial committee has been established to provide the ground work of the ratification. Now the process ratification is underway in accordance with the Law No. 24 of 2000 on International Agreements.

For empowering women with disability, the Ministry of Women Empowerment and Child Protection have reviewed national legislation on anti-discrimination of women with disability and elderly; built capacity for women with disability through seminars and workshops in many provinces; advocated for the rights of women with disability and in 2009, established two centres for counseling and providing information for women with disability in the provinces of Jambi and East Java.

In health, to avoid misconceptions about what comprises disability, in 2009 guidelines were passed for health screening and functioning ability for people with disability. This was important for the assessment of individuals with disability who are seeking jobs or enrolling for school. To minimise the prevalence of disability, The Ministry of Health conducted training for early detection of disability.

In accessibility to information and technology, Indonesia has SIBI (Indonesian Sign Language) for the deaf community and for those with visual impairment, 150 books have been translated into digital books, as well as in Braille. Indonesia has two web sites accessible for people with disability. For those with visual impairment it is www.mitranetra.org.id and for the deaf I-CHAT (I can hear and talk). This site is provided by the National Telecommunication Company.

Education for people with disability in Indonesia is provided both in special schools and schools that are inclusive from primary to secondary levels. There are now 640 disability-inclusive schools around Indonesia and recently the University of Indonesia and University Islam Jogyakarta have become inclusive for students with disability.

Since the general election in 2004, people with disability in Indonesia have access to the vote and to be elected. During 1999–2001 Indonesia's president, Mr Abdurrahman Wahid had a disability.

Challenges of implementing disability rights in Indonesia

According to the National Social and Economic Survey 2009, Indonesia has 2.1 million people with disability (National Board of Statistic: 2009). Even though there have been a number of achievements, needs have still not been met as in a country the size of Indonesia there are considerable challenges. Some of the key challenges are:

There are many laws and regulations related to disability that are not enforced. For example, Article 29, para (1) Law No. 4/1997 states 'or those are not providing accessibility as mention on article 10 this Law or who are not giving opportunity and equal rights for students with disability in each range, kind and level of education as mentioned on article 12 this Law shall get administrative punishment'. In fact many schools — both government and private — are inaccessible for people with disability. In addition, the content of the law remains unclear. The article stipulates that 'administrative punishment' will be extended but there is no regulation about how the punishment should be administered or who should do it.

Since 1997 Indonesia has a Law on Disabled Persons which requires equal opportunity and rights of people with disability in many aspect of life. Unfortunately, among stakeholders disability is still seen as a welfare issue.

In accordance with the principle of decentralisation local governments are authorised to manage and develop their own provinces. The implementation of programs for people with disability depends on how much budget each province allocates.

Notes

[1] See UN ESCAP E/ESCAP/APDDP(2)/2 ' 13November 2007.

[2] Republic of Indonesia, Law No. 4/1997 on Disabled Persons.

The role of disabled person's organisations in development: Key principles and strategies for success

Lesley Hall, Australian Federation of Disability Organisations and
Therese Sands, People with Disability Australia

This paper addresses the importance of involving people with disability and their representative organisations in the development process. It looks at what constitutes a disabled person's organisation (DPO), how people with disability organise at national, regional and international levels and the importance that the United Nations Conventions on the Rights of Persons with Disabilities (CRPD) places on their involvement. Based on our experience, we provide practical strategies on how to work with DPOs and argue that if DPOs are not involved in the development process then inclusive development for people with disability is not possible.

'Nothing about us without us' was the catch cry of people with disability as they participated in the development of the CRPD. The Convention came into effect in 2007 and was ratified by the Australian Government in July 2008. The principle of including people with disability in decision-making processes has been embedded into the Convention. In particular articles 4, 29, 32 and 33 as included below.

Article 4 — General obligations

> *Part 3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.*

Article 29 — Participation in political and public life

> *States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake to promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties; forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.*

Article 32 — International cooperation

> *1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:*
>
> - *Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;*
> - *Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;*
> - *Facilitating cooperation in research and access to scientific and technical knowledge;*
> - *Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.*

Article 33 — National implementation and monitoring

> *3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.*

From the above articles of the UN Convention it can be seen that Disabled Persons Organisations should be involved in all areas through article 4 which is the general obligations as well as in civil and political life, international development and the implementation and monitoring of the convention.

The role of DPOs

It is important to remember that the Convention provides a blue print for what type of society should exist for people with disability. How does this look for the disabled? The answer must come from within the particular community. These people may or may not be represented by a DPO.[1]

DPOs can be organised in different ways. They can operate internationally, nationally, regionally or at the local level. Some have membership that spans the spectrum of disability while others are formed around a particular type. Disability-inclusive development means that people with disability should be part of every program and project. Good development practice involves a rights-based approach and includes forming a true partnership that empowers people. DPOs must be central to decision making that affects people's lives. A human rights approach to disability-inclusive development must be genuinely inclusive of people with disability and their representative organisations.

People with disability and DPOs, including in Australia, were integrally involved in the development of CRPD. This is the first Convention to comprehensively engage civil society in negotiations and to include provisions for the ongoing engagement with DPOs in CRPD implementation and monitoring.

DPOs have also been working together for the ratification, implementation and monitoring of the CRPD and will be central to the process of interpreting it so that governments will implement it appropriately. People with disability have a real 'ownership' of CRPD — it's about us; we helped create it; and we own it by being involved in implementation and leading NGO monitoring. This means working with DPOs to understand the CRPD, including its practical application. For example, Article 19, Living Independently and Being Included in the Community, includes a phrase — 'Persons with disabilities have the opportunity to choose their place of residence'. The concept of 'choice' may mean that if a person wants to live in an institution they should be able to do so. But 'choice' can be understood only from the point of view of 'human dignity' — the end point for all human rights. This means that building or supporting institutions is not in line with human dignity and cannot be considered as viable housing options by governments, development organisations or donors.

DPO expertise

DPOs, including those in Australia, have expertise that can guide development and donor organisations. This expertise is often not acknowledged or used but includes:

- linkages and partnerships with DPOs in the region through membership and networks (part of the broader, global disability rights movement);
- linkage points for people with disability in a country;
- lived experience of the cultural understanding of disability;
- lived experience of how 'disability' is being acknowledged or addressed by village and church leaders, local, provincial and national governments; and
- practical knowledge of inclusive practices, consultations, and solutions.

Australian DPOs have lived experience of what works and what doesn't in support systems, policy and practice as the country has a long history of resourcing support systems and services for people with disability. This can assist with ensuring that 'bad' practice, or non-rights based practice is not transported to other countries.

Development and donor organisations programs need to be 'on tap, not on top'.

An excellent resource is *Equalise It! A Manifesto for Disability Equality in Development Cooperation.*[2] Points from this manifesto include:

- DPOs are the leaders in their development (they may require transfer of skills and leadership development);
- people with disability and DPOs need to determine and control the design and outcome of development programs;
- development and donor organisations must be 'allies' in development (the disability rights movement – realisation of CRPD), not 'experts'.

The manifesto includes a checklist for allies. Development and donor organisations, disability service providers, NGOs and other intermediaries need to have in place a culture and operations that:

- ensure that people with disability/DPOs have identified the need for programs;
- ensure that people with disability/DPOs are not used to legitimise funding applications or requirements;
- ensure that people with disability/DPOs are genuinely involved as partners in all areas of program design, delivery, evaluation and review;
- ensure that the CRPD is the framework that underpins programs; and that the CRPD is understood and applied in line with the expertise of DPOs. To do this partner with Australian DPOs and DPOs in-country;
- ensure skill and resource transfer to DPOs in order to build DPO capacity, sustainability and self-representation;
- champion leaders with disability;
- change governance, staffing and operational structure to increase the numbers of people with disability working at all levels of the organisation;
- change internal and external policies and practices to remove discrimination from your organisation; and to enable a voice for people with disability within your organisation (advisory groups); and
- formalise networks and partnerships with DPOs.

Note

[1] Office of the High Commissioner for Human Rights. Civil society questionnaire.

[2] For more information see http://www.daa.org.uk/index.php?page=equalise-it

Progress for people with disabilities in the Solomon Islands

Joel Viriala, People with Disabilities, Solomon Islands

I'm a member of People with Disabilities in the Solomon Islands. My country comprises 962 islands of which 147 are inhabited. The archipelago stretches 1,448km to the southeast of Papua New Guinea. The Solomon Islands population is estimated to be 510,000 according to the 1999 Solomon Islands National Population Census. The official language is English but there is a local language and 18 dialects. The Solomon Islands gained independence from Great Britain in 1978. There are ten provinces.

People with Disabilities (PWD) was established in the 1990s and is an advocacy organisation mandated to promote and advocate for people with all types of disabilities. It is registered under the Charitable Act. People with disability automatically become a member of PWD. We continue to look for opportunities to build partnerships with other organisations which work for, or with, people with disability. This will expand our knowledge and build expertise to advocate effectively and efficiently in our country. PWD aims to train its members and most importantly, their families, to become advocates on disability issues. PWD is a volunteer organisation managed by an executive committee which is elected by members of the AGM every three years. The executive comprises a president, secretary and four members.

According to the National Disability Survey conducted in 2005 there were about 14,403 people with disability in the Solomon Islands — it will now be higher. Of these, 6,505 (45 per cent) are females, 25.57 per cent are between the ages of 0–20 years and 26.1 per cent between the ages of 21–50 years. The three most prevalent disabilities in the Solomon Islands are — blindness or vision impairment (27 per cent); physical impairment (20 per cent); deafness or hearing impairments (17 per cent).

PWD achievements in 2009/2010

PWD has been engaged in a number of activities the most important of which is on-going advocacy. In 2009, the PWD president was elected to be the co-chairwoman for the Pacific Women's Association and attended the first Pacific Island Forum meeting in the Cook Islands. PWD actively participated in the consultations surrounding the Disability Bill which will hopefully be tabled at the next Parliament meeting. In 2009, the PWD applied for support for internal capacity building and submitted a project proposal to the Disability Rights Fund (DRF). In 2010, the DRF funded four projects and so far two workshops have been conducted. The first was held on the island of Savo in the centre of the Solomon Islands and the second in Honiara City. In February and March 2010, PWD attended a six-week training at the Queensland University of Technology and Christian Blind Mission in Australia. In 2010, further capacity building was funded.

Organisational challenges

PWD, like any other organisation, faces many challenges. As a small organisation run by volunteers and with very limited government support it remains rather weak and advocacy and lobbying are difficult. As a result, most people with disability still do not know their rights. Lack of knowledge of human rights results in people with disability being abused and lack of access to education remains a major problem for people with disability.

Another challenge is charity-based ideas. Many organisations working in disability consider their involvement as charity and people in the Solomons tend to have a charity mentality. This has been difficult to change.

Partnerships and progress

We are humbled to be able to partner with the following organisations and I am happy to say that our partnerships have certainly made great changes in our resolve to advocate effectively and efficiently. The Australian Pacific Disability Support is the first ever partner in disability for PWD since 2007. APIDS provides funds which have assisted PWD in fixing their computer, to get new equipment and provides the transport cost for the executive members to attend the executive meetings.

Our partnership with the University of Technology and CBM began in 2009 and resulted in the Australian fellowship training for 11 participants from PWD. Four CBM workers attended this training and it produced 11 trainers. This partnership continues and we look forward to other partners. Australia and PWD and its neighbours have learnt from this partnership.

We have learned that good leadership is extremely important and particularly important for the sustainability of PWD. We have learned the importance of strengthening the organisation for future generations and that accountability and good governance of the organisation will also build our reputation — with a good reputation, more partners may assist. We have learned that networking and building stronger networks with local, regional and international bodies brings opportunities for further partnerships. Partnerships are important because they help to provide expert training for people with disability about their rights, provide training.

Our Australian partners have helped us with advocacy efforts. And we are learning new advocacy techniques which will be very important in working with communities as it will encourage active participation of communities in identifying gaps. Participants have been able to see where some gaps are in advocacy and realise the need to work towards inclusive approaches using the CRPD.

Future action

We need further training in human rights and people with disability need to be trained to actively advocate for their rights. This process is long and challenging. Our focus now is on helping the Solomon Islands Government and building the capacity of the DPOs. We need more partnerships between Australian DPOs and disability organisations to raise awareness on disability and to lobby our Government to ratify the CRPD and to see disability on a broader scale. Finally, PWD, I believe, through partnerships, will develop practical and advocacy efforts to remind Government of its obligations, and through partnerships there will be more windows of opportunity. From small things, big things do grow.

Appropriate mobility equipment: A prerequisite for disability inclusive development for people with a mobility disability

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Elsie Taloafiri, Community-based Rehabilitation Unit, Solomon Islands

Wheelchair provision in low income countries is at a turning point, with increased recognition of the need to provide appropriate wheelchairs. The World Health Organisation (WHO) estimates that one per cent of the global population need a wheelchair. In low income countries, only five to 15 per cent of people with disability have the devices they need. An estimated 20 million people living in low income countries require a wheelchair but do not have one. Many more have a wheelchair which does not meet their needs (Borg, Khasnabis: 2008).

The right to appropriate mobility is affirmed in the UNCRPD and in August 2008 the World Health Organisation (WHO) launched *Guidelines on the Provision of Manual Wheelchairs in Less Resourced Settings.* This is an important milestone in the improvement of wheelchair provision for people living in such settings. WHO is continuing this work through the development of a training package to support the delivery of training in wheelchair provision for local rehabilitation and health professionals or volunteers, due to be launched in December 2011.

There continue to be many barriers preventing wheelchair users from accessing a wheelchair that meets their needs. These include lack of appropriate, quality units and staff trained in the provision of wheelchairs. The most common approach to wheelchair provision in low income countries has been through donation of inappropriate Western designed orthopaedic style wheelchairs.

This paper offers an example of appropriate wheelchair provision working in the Asia Pacific region through a partnership project between Australian International NGO Motivation Australia and a Government disability service provider in the Solomon Islands.

Motivation Australia

In over 30 low income countries, Motivation has worked closely with local government and non-government organisations as well as wheelchair users to implement sustainable programs to improve wheelchair provision. Motivation's work includes appropriate wheelchair design and production, capacity building to increase effective service delivery and training of local clinical and technical staff in wheelchair provision. Motivation Australia was registered in South Australian in 2007 and focuses on the Asia Pacific Region. The organisation's mission is to enhance the quality of life of people with mobility disability.

Solomon Islands context

The Solomon Islands has a population of over half a million, living on 342 islands across 1,500 km. Eighty per cent live in rural villages, many accessible only on foot. Using the WHO statistics, there are an estimated 5,000 wheelchair users, although the National Disability Survey identified no more than 1,500. There is extremely limited funding available for disability services. The Community-based Rehabilitation Unit (CBRU) is under-staffed and under-resourced. In 2007, recognising the need for wheelchairs the CBRU purchased 20 wheelchairs at a cost of A$800 — most broke down within six months in the hard rural conditions. At that time, the CBRU also recognised a lack of the knowledge and skills among staff necessary to provide wheelchairs to meet the needs of users.

The CBRU is a department of the Rehabilitation Division, Ministry of Health and Medical Services, Solomon Islands. The Unit has 18 CBR aides spread over eight provinces responsible for providing services for up to 14,000 people with disability living in the community. The Unit's work includes the provision of assistive technology, including wheelchairs.

Motivation Australia and CBRU partnership

In late 2007 the CBRU requested assistance from Motivation Australia to enhance their wheelchair provision services. In May 2008 Motivation Australia and the CBRU jointly conducted a feasibility study that included consultation with all key stakeholders. These included the national Disabled Persons Organisation and People with a Disability Solomon Islands. All agreed that the most appropriate organisation to provide wheelchair services was the CBRU, working with the National Referral Hospital. In 2009, Motivation Australia and the CBRU commenced a program to initiate a pilot wheelchair service in Honiara.

Program activities

Initial training

A two week wheelchair service delivery training course was delivered by Motivation Australia in Honiara, coordinated locally by the CBRU. Through the course, three senior rehabilitation staff from the CBRU and one CBR Aide were trained in the clinical skills involved in wheelchair service delivery including assessment, prescription, fitting, user instruction and follow up. In a parallel course two technicians were trained to assemble, fit and maintain two different designs of robust wheelchairs. These, designed by Motivation with input from wheelchair users living in low income countries, are produced in China and flat-packed for shipping to local wheelchair services for assembly.

Pilot service

Following the training, the staff began to work with wheelchair users in and around Honiara, gaining skills and experience in wheelchair service delivery and receiving feedback from users. This was very positive, so that requests began to come in from users living in outlying provinces. The CBRU and Motivation Australia stayed in close contact, and Motivation Australia carried out a support visit in late 2009.

Further training

In 2009, the CBRU requested Motivation Australia's assistance to expand the service to five provinces. Funding was secured through AusAID and a second course held in 2010. This trained a further six CBR aides and three physiotherapists in wheelchair service delivery. The course material was a pilot WHO training package, and was co-delivered by Motivation Australia and the CBRU. A number of the sessions were delivered by wheelchair users living in Honiara. As four of the CBR Aides working in the Provinces work in isolation, these were also trained in the skills required to assemble, fit and maintain wheelchairs. They are now able to provide wheelchairs to users in their province.

Increased product range

As a result of the program, the CBR Unit is now able to offer a wider range of wheelchairs for users living in the Solomon Islands. This includes a rural 'rough' terrain wheelchair, a four wheel robust folding wheelchair, and an orthopaedic style wheelchair for hospital or temporary use. All are now available with a pressure relief and posture control cushion. Later in 2010, the program will introduce a children's wheelchair with the potential for local modification to meet the needs of children who require additional postural support.

Outcomes for wheelchair users

In 2008, fewer than 50 people received a wheelchair in the Solomon Islands. From 2009 to mid 2010 180 people received a wheelchair.

Most importantly, the physical, environmental and lifestyle needs of each user have been assessed, with users being given the opportunity to participate in deciding the most appropriate wheelchair for their requirements. Each user is training in how to use their wheelchair, getting in and out, being as mobile as possible and maintaining the chair in good working order it. For people at risk of developing a life threatening pressure sore, extra education has been given to help them avoid this.

A number of wheelchair users have reported positive changes in their lives as a result of the improved mobility, including being able to work, reduced time away from work, being more able to participate in activities around the home and to access the community.

Lessons learnt

Valuable lessons have been learnt from this partnership. These include:

Start small

The pilot program in Honiara provided the CBRU senior staff and management an opportunity to understand how wheelchair provision can work within the Solomon Islands before they tackled providing services on a larger scale. The pilot program provided the CBRU with an opportunity to have a greater sense of ownership of the program as a whole.

Communication

Good communication between both partners was essential in ensuring success. Motivation Australia's remote support has only been possible through regular and consistent communication from the Solomon Islands.

Work with the existing infrastructure

Working with the CBR program in the Solomon Islands has enabled the program to be well integrated within the existing disability services and networks. This offers the program far greater potential for long term sustainability, particularly as the CBRU is government funded.

Building awareness

The program has now reached a stage where increasing awareness of the wheelchair service is next. With staff now trained and wheelchairs available, the CBRU is keen to ensure that users, their families and communities are aware of the service, understand that a wheelchair needs to be properly prescribed and fitted, and that they may access the CBRU for this service. The CBRU and Motivation Australia are also closely monitoring how women access the service and plan to ensure that access is equitable between genders.

References

Borg, Khasnabis 2008, 'Guidelines on the Provision of Manual Wheelchairs in Less Resourced Settings', World Health Organisation.

Disability inclusion in Papua New Guinea from personal experience

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Introduction

The percentage of people with disability in Papua New Guinea is not known but based on the World Health Organisation estimate of 10 per cent, there are at least 600,000 people out of a total population of 6.2 million, with a disability. This will increase due to a combination of poverty, conflict, malnutrition, HIV/AIDS, natural disasters and an ageing population. People with disability in PNG consistently face barriers to education, exclusion from the workforce and most often do not have access to the basic aid and specialised equipment which would allow them independence. This means that not only are people with disability themselves affected, their families and communities are also denied progress.

Legislation

The PNG Constitution's National Goals and Directive Principles in Goal 1 are Integral Human Development (1), (2), (3), (4) and Goal 2, Equality and participation (1). Both recognise the rights of people with disability. PNG is in the process of signing the United Nations Convention of Rights of People with Disabilities (CRDP). In 2009, the Government endorsed the National Policy on Disability but has yet to enact disability legislation.

Services for people with disability

The Government of PNG provides services for people with disability through the Department for Social Welfare and Community Development. One of the Government's milestone initiatives has been the creation of a desk for disabled and elderly persons headed by an Assistant Secretary. In addition it has also established a Secretariat to cater for these special people's needs. All other services are provided for by NGOs, Faith Based Organisations and Disabled People's Organisations (DPOs).

Currently, Papua New Guinea does not have a disability-inclusive education system. The only special education centers are run by NGOs and Faith Based Organisations. Nor are there public health services for people with disability and the limited specialist care available is privately run or managed by NGOs and is mostly located in urban areas. This contributes to the appalling state of health of people with disability in PNG especially in the rural areas.

There is an urgent need for both government and the private sector to collaborate with DPOs and come up with a special insurance cover for employed people with disability due to the fact that they have special needs.

Accessibility to services

All public transport (air, sea and roads) are inaccessible to people with disability. There are no public recreational facilities to cater for people with disability. At the same time, there are no separate public toilets for people with disability to use whilst they are out and about. Current educational facilities are inaccessible or don't have special facilities/ learning aids for people with disability. No high rise buildings (prior and under construction) have disabled people's access. The Supreme and National Court do not have disabled person's accessibility. Even the prison system in the country is not conducive to caring for and rehabilitating convicted people with disability.

Social activities

Although there are no disability-inclusive sporting facilities for people with disability, most make do with public facilities that cater for able bodied people. There is a National Disabled Sports Association that caters for people with disability, but it is more focused on the international scene rather than the local. Last year, for the first time, people with disability were allowed to participate in the PNG Games representing their provinces. Many won medals and in doing so created awareness that raised the profile of people with disability.

My own experiences

I am a career Prison Officer with the PNG Correctional Service who had a car accident in the line of duty which resulted in having my right leg amputated. After that, I managed to attend university under private sponsorship and graduated with a degree in social sciences (University of PNG 2001). Upon my return I was not accorded recognition of my situation or academic achievement although I was appointed to act in a couple of positions. I was only recognised after 20 years (2009) of service by being promoted to the rank of Sergeant.

I have been invited by friends to socialise but once we arrive at the night clubs, the proprietors only allows my able bodied friends to enter whilst I am restricted citing 'company policy' does not allow a person like me to enter for safety reasons. Sometime this leads to heated arguments with the security personnel.

I have been provided accommodation by my employer but the recommendations by my doctor to have it modified to suit my needs have not eventuated since my accident in 1990. I purchased an artificial limb but am unable to use it because of the conditions of the public roads such as lack of proper pedestrian footpath, escalators in high rise shops, overhead crossings, specialised transport etc.

The way forward

There are government agencies tasked with the responsibility for making PNG a disability-inclusive society. These include the Land Transport Board, Building Boards, and Department for Community Development, Health Department, Education Department, Department of Justice and Attorney General, Correctional Services. What is lacking is dialogue and collaboration among them and with the DPOs. With the government endorsing the National Disability Policy (2009), the time is right now for the appropriate stakeholders to push for enactment of appropriate Disability Persons legislations.

Conclusion

I believe disability issues must be mainstreamed as a cross cutting issue similar to HIV/AIDS. The same amount of resources pumped into HIV/AIDS awareness by stakeholders must compliment disability awareness.

Support for disability-inclusive activities in Papua New Guinea: An update

Divine Word University, Madang

Overview

There have been a number of important recent developments in PNG towards more disability-inclusive development, in particular the active involvement of the Government of PNG. In brief, these achievements are:

- The Papua New Guinea (PNG) Government endorsed the National Policy on Disability in 2008, developed under the leadership of Dame Carol Kidu (Minister for Community Development).
- The PNG Government provides ongoing budgetary support for disability-inclusive development – a key point of difference with most Pacific nations.
- A National Advisory Committee on Disability has recently been established to oversee and coordinate implementation of the national policy on disability.
- Dame Carol Kidu has requested Australian support, in discussions with Bob McMullan, to facilitate ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD).
    - AusAID has indicated that it would be pleased to work with and support Dame Carol's efforts to understand what would be involved for PNG to ratify the CRPD.
    - AusAID has placed a Development Program Specialist – Leonie Whyte – in Dame Carol's department, located within the Governance team that is responsible for implementing PNG's Disability Policy.
- As an early response, PNG will benefit from the training being provided by the Australian Human Rights Commission, under Australia's Public Sector Linkages Program, to build capacity and knowledge of DPO's and government representatives to progress disability issues.
- AusAID is also supporting CBM/Nossal to conduct introductory training on Disability-Inclusive Development for Community Development and the National Advisory Committee on Disability.

Background

The Churches and non government organisations are responsible for the majority of services in the area of disability. Over the last 10 years disability services have expanded to most provinces with a major emphasis on community based rehabilitation (CBR), providing awareness of disabilities and encouragement and training to families and communities to enable the disabled to lead a better quality and more independent life. Callan Services, an agency of the Catholic Church, is the main provider.

While schools specifically catering for the people with disability were established in the 1960's and 1970's (in particular for the hearing and sight impaired) the 1993 Department of Education policy on National Special Education shifted the focus of these institutions to prepare children with disabilities to be integrated into mainstream schools. However, with only around 50 per cent of all children attending primary education it is expected that many children with disability would not be attending school.

In general, there is a lack of knowledge and resources for managing disabilities in many communities, and the cultural and traditional perspectives have a great influence over the lives of people with disabilities. Many people are unable to join community life, go to school or work; often they are not able or not allowed to leave their home.[1]

PNG Government support

After launching the Disability Policy PNGK1.1 million was allocated under the development budget in addition to PNGK780,000 in the recurrent budget to support implementation. The Disability Policy aims to shift discussion in PNG from welfare approaches to recognising that people with disability should be included in the mainstream of social and economic life.

Implementation of the National Policy has begun including the establishment of the national focal point and a National Advisory Committee on Disability. The Ministry of Community Development, through the Department of Community Development, Disability and Elderly Unit, is the National focal point. PNG is in a good position to progress disability issues owing to strong Ministerial endorsement but progress in implementation is slow. The Government budget goes largely towards disability program activities and grants to disability equipment-providing agencies and self help organisations.

Australia's support

As the major donor for disability inclusion in PNG, Australia supports capacity building, eye care, education and community programmes. The details of the programmes are:

Capacity development

- Future support for DPO capacity development in advocacy and leadership through a partnership between Australia, New Zealand and the Pacific Disability Forum.
- Capacity building on the CRPD administered by the Australian Human Rights Commission and the Pacific Disability Forum for DPO members and government representatives, funded through the Pacific Governance Support Program

Eye Care

- $387,300 from the Avoidable Blindness Fund for the International Centre for Eye care Education's 'Expanding eye care services in Papua New Guinea' activity focusing on better access to eye care and affordable spectacle services including human resource and infrastructure development.
- $346,000 from the Avoidable Blindness Fund for the Institute for Eye Research Ltd. for the project 'Measurement of barriers to eye care, utilisation of services and vision-specific quality of life Papua New Guinea'.
- Support to the Divine Word University in Madang for training of eye care personnel, administered by the Fred Hollows Foundation New Zealand as part of a delegated funding arrangement with NZAID's Pacific Regional Blindness Prevention Program.

Education

- Australia's Basic Education Development Program has supported the Department of Education to produce revised Infrastructure Guidelines for Elementary, Community and Primary Schools. The revised guidelines now have a section dedicated to 'designing for the disabled' which teaches schools ways of making it easier for a person with a disability to access school facilities. These guidelines were distributed to all schools in 2010.
- Australia's Education Capacity Building Program (ECBP) has provided inclusive education disability training to 50 Special Education Resource Centre staff and 25 teacher education lecturers. ECBP has also
- trained approximately 300 school based counsellors and a component of that training includes supporting children with disability. ECBP has also been assisting the Department of Education to develop a number of cross-cutting policies, including on HIV/AIDS, gender and behaviour management. All these policies encourage the Department, the provinces, the schools and the communities to ensure that children with disability are not disadvantaged in the education system.

Community Programs

- The Sport for Development Initiative (SFDI) is a program of support by AusAID to the PNG SFDI and its key partner stakeholders. The SFDI goal is 'to establish effective and sustainable systems for personal and community development through sport'. A guiding principle of the program is 'Inclusiveness' and including people with disabilities. As well as the general opportunities for support, there is also specific support budgeted annually towards the Sport Ability Program/Disability Sports.
- Through the Community Development Scheme and Democratic Governance Transition Program grants have been provided to organisations for disability programs including training, rehabilitation and resource development.
- Funding to Leprosy Mission Australia through the AusAID-NGO Cooperation Program assisting families and communities affected by leprosy related disabilities.

Note

[1] http://www.dwu.ac.pg/network.htm.

Urbanisation in the Pacific Islands context

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Background

In 2008, for the first time in history, some 50 per cent of the world's 6.7 billion people were estimated to be living in urban areas. Approximately 30 per cent of these urban dwellers are living in 'slums'. By 2030, 60 per cent of the world's population is expected to be urban (El Sioufi, 2009). Most of this urban change and growth is happening in developing regions, including Africa, Asia, and small island countries such as in the Pacific. All will continue to be subject to rapid rates of urbanisation in the future.

In all parts of the world, towns and cities are being subject to new and influential forces requiring stakeholders to rethink how best to manage the urbanisation process. The current millennium, especially the post 2005 period, has seen the elevation of new drivers of urban change in the Pacific region, specifically climate change, natural disasters, and the global financial crisis (GFC). These drivers have amplified and further highlighted the adverse symptoms of unmanaged urbanisation, including food insecurity, increasing informality, resource depletion, declining law and order, and environmental degradation. Understanding urbanisation and how it has evolved and been shaped in the Pacific region, is essential to better managing the urbanisation process if towns and cities are to be sustainable.[i]

The nature of Pacific urbanisation

Urbanisation is a cross-cutting and recent phenomenon in the Pacific. This movement of people from rural areas to towns and cities is accompanied by major economic, social and environmental change. In the Pacific it has been characterised by growing urban-based economies and demographic change, set in the context of generally mediocre economic performance. Pacific urbanisation has seen pronounced changes in:

- physical patterns of towns and cities;
- behavior, including values, norms, attitudes, and expectations;
- consumption patterns;
- shift from community control systems to State rules and regulation; and
- lifestyle, family, and social changes including use of customary land as a commodity.

An understanding of the evolution of urbanisation in the Pacific Island Countries (PICs) is essential to responding to Pacific urban growth issues. Urbanisation accelerated in the post colonial era after PICs gained independence. Colonial administrators – German, British and Australian — oversaw well laid out towns, and were strict in dealing with rural urban migrants who did not have authorisation to travel. Anyone without formal permission to work and live in a town was sent back to their village. After independence, the regulatory approach to restricted movement was downgraded and the tide of free and uncontrolled movement commenced. The fabric of towns and cities was slowly transformed, with urban villages, towns and cities becoming a melting pot of modern and traditional ways (Jones, 2010).

As PICs have become urbanised, the urban population has grown faster than in rural areas and as PIC economies have developed, an increasing share of national wealth, (GDP), has been produced in urban areas. Urban economic activities have strengthened the viability of rural economic development by providing markets, processing centres and trans-shipment points for rural produce and goods. In this context, urbanisation in PICs can be viewed as the spatial translation of the production structure of their economies across varied geographical island settings. In some PICs, this has been characterised by a relative declining share of primary (rural agricultural) production sectors, and an increased share of secondary, industrial, and tertiary service sectors, all primarily located within urban areas. As both rural and urban areas remain economically and socially connected it is not possible to understand the situation in urban areas without understanding the economic and social underpinnings of rural areas, and vice versa.

Urbanisation has led to increasing pressure on urban services and infrastructure, such as local road networks, water supplies, sanitation, land supply, garbage collection and disposal, as well as governance and institutional arrangements (Jones, 2004). The unlocking and mobilisation of land for urban development, primarily customary lands, continues to be a major cross-cutting theme which distinguishes the Pacific urbanisation process from urbanisation in other world regions. Other features of PIC urbanisation, such as income inequality and poverty, growing peri-urban areas, rising youth numbers, and limited institutional and technical capacity, are now commonplace in all less developed countries (UN-Habitat, 2009).

The permanency of settlements

As rural urban migration to towns and cities has continued, the concept of the 'village in the city' has become entrenched in the physical form of Pacific towns and cities. More and more people moved to towns and cities, but think, live and behave like rural villagers within an urban setting. As a result, Pacific towns and cities are now a mix of:

> permanent and semi permanent villages, comprising informal settlements, formal settlements and traditional villages, such as in Suva, Apia or Port Moresby, for example; and
>
> planned residential areas with housing of various standards.

Both areas are increasingly hidden behind security grills and fencing to address urban security concerns.

In Port Moresby, for example, settlements accommodate just under half of the urban population, namely, 200,000 persons, which are spread over 99 settlements and have been characterised as carrying out a traditional way of life (UN-Habitat, 2008: UN-Habitat, 2004). In the Pacific region, urban villages and settlements, illegal or otherwise, have strong kinship and ethnic ties to rural areas and/or outer islands. Port Moresby settlements have been described as 'cosmopolitan networks of tribal groupings or anarchical sub-cultures, which have been defined by ethnicity and regionalism within an urban context' (Muke, Mangi and Kimbu, 2001:7). Settlements are now a permanent and increasingly dominant feature emanating from the urbanisation process in the Pacific Region.

The robust social, cultural and economic connectivity between urban and rural areas, including affiliation to ethnic and kinship groups, land, outer islands and the like, reinforces the perspective that the urban-rural divide, including poverty, is best viewed as a continuum, rather than a rigid dichotomy (Jones, 2010). The blending of the socio cultural order into the urbanisation process shaping Pacific towns and cities, including the control systems, processes and mechanisms that apply in the rural village context, has been termed the *cultural permeation of urban areas* (Office of Urbanisation, 2010). Such concepts are fundamental to understanding the patterns of Pacific urbanisation. The manner in which such changes associated with the urbanisation process are played out in day to day life in PIC towns and cities are summarised in Table 1.

The diversity of Pacific towns and cities

The 2010 midyear population for the Pacific region, as estimated by the Secretariat of the Pacific Community (SPC), was 9.8 million. Based on the last census the average percentage share of urban populations in PICs was approximately 50 per cent. In terms of actual persons living in Pacific towns and cities, just over 2.5 million persons (26 per cent) of a total population of 9.8 million were residing in urban areas. As most PIC urban boundaries exclude their adjoining and rapidly growing peri-urban areas, the real rate of urbanisation in PICs is under enumerated and regionally is likely to be far greater than published figures. This upward trend is significant, as it implies that the increasing concentrations of the poor and those vulnerable to urban poverty are also under enumerated.

Some 17 of the 21 PICs in Table 2 have 20 per cent or more of their populations residing in urban areas, while some nine of the 21 PICs have 50 per cent or more of their populations living in urban areas. Urbanisation rates have been highest in the smaller states comprising Micronesia. Significantly, in nearly all PICs, urban growth rates outstrip national growth rates. Urbanisation would be higher in some PICs if not for emigration, which has capped population growth rates in PICs such as Samoa, Tonga and Cook Islands. Due to emigration others, such as Niue and Tokelau, have had negative population growth.

Most Pacific urban residents live in the larger PICs of Melanesia — around 1.6 million of a total 2010 Melanesian population estimate of 8.6 million persons. The largest proportions of urban populations are found in Micronesia, followed by Polynesia and Melanesia (see Figure 1). Four of the seven Micronesian countries have urban populations in excess of 60 per cent. PNG has the largest land mass in the Pacific and the largest population – 6.7 million or 68 per cent of the Pacific regional population of 9.8 million persons. This is reflected in the fact that the largest urban populations and the largest city in the Pacific region, Port Moresby, is in PNG.

Based on the last PNG census in 2000, the urbanisation rate for PNG was 13 per cent or some 674,802 persons living in towns and cities. By 2010, the National Urbanisation Policy for PNG, 2010-2030, estimated the PNG urban population as being approximately 1 million persons (Office of Urbanisation, 2010). The PNG urban population is more than the entire 2010 populations of the Pacific sub-regions of Polynesia (663,795 persons) and Micronesia (547,345 persons).

Table 1: Pacific Urbanisation: the Rural Urban Continuum

PIC Socio-cultural Feature	**Rural Setting**	**Urban Setting**
1. Marriage	* can be prearranged - no say in choice of husband or wife * may involve 'bride price' payment * large ceremonial obligations involving family, village, clan, tribe and so on * marriage restricted to being within similar island - geographic group, tribe, clan or cultural group	* larger choice of partner * women especially have greater freedom from village - family socio cultural ties and restrictions * choice of venue and ceremony * marriage within or outside of settlement and urban village
2. Births and Deaths	* large ceremony on reaching one year of age * death is mourned by family and clan - all work stops * burial within 2-3 days * burial place can be next to house	* mourning for a death can be over a lengthy and extended period * burial can occur over extended period - mortuary allows longer period while waiting for family members * use of public cemetery for burial
3. Language	* own dialect in homogenous groups * dialect not physically recorded	* exposure to English * English training centres * exposure to range of dialects *exposure to a range of languages
4. Economic Development	* development based on gardening - farming * subsistence based * small scale commercial activities * work only as needs have to be met * informal sector employment * little regulation	* residents have some or no gardens * reliance on local produce and imported goods * varying levels of informal and formal sector employment and opportunities * rules and laws impact on business opportunities
5. Dress and Appearance	* traditional dress reflects importance and seniority * dances and ceremony on special occasions	* dress modern style anytime * dancing and recreation anytime * no peer group pressure on style - type of dress
6. Housing	* traditional design * traditional materials * special built structures reflect functionality * accommodates extended family	* permanent and semi-permanent materials used * modern house provides many functions * connected to modern services
7. Kinship Arrangements	* strong kinship arrangements handed down through generations * social and biological basis * socialise within kinship group * strong family and wider clan care and control of children * homogeneous communities based on unity of families and clans	* concerned with only immediate social and biological kin * can mix with any group * breakdown of parental and wider family care * heterogeneous communities - migration maybe individual rather than whole of family * urbanisation impacts on children including dietary changes, abuse, exploitation, etc
8. Land	* customary ownership * family and wider group such as clan involved in land distribution * land rights oral - not recorded in writing * land use rights can be fluid and not definitive * lands associated with families, clans and tribes	* land can be freehold, lease or customary arrangement * land has greater economic use and land value * land ownership endorsed by Courts and recorded in registers * land used as a commodity * individual title can be given to land * informal arrangements on use and ownership
9. Settlement Patterns	* dwellings in contained village arrangement or dispersed * traditional layout of buildings * low density, minimal or no reticulated services * village occupants associated with clear land areas for gardening and farming * limited transport systems	* planned and unplanned settlements * varying degree of services and infrastructure * high density * western style architecture * environmental degradation * access to airports and ports - greater flexibility of movement * high urban security, law and order concerns

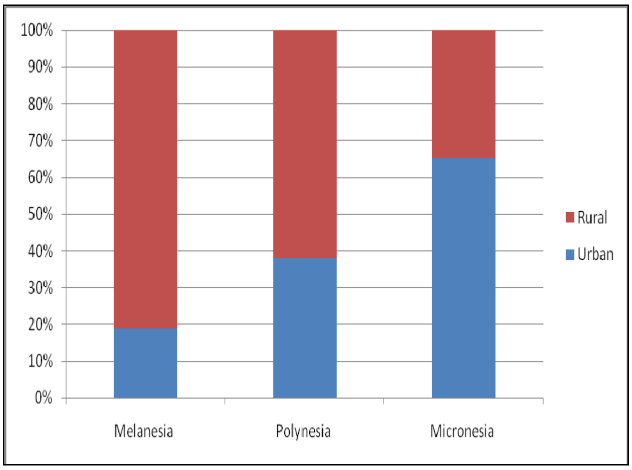
Source: Adapted from the Office of Urbanisation, 2010

Table 2: Key Population Indicators for Pacific Island Countries, 2010

Country and Pacific Sub-Region	Mid-Year Population Estimate (2010)	Population Growth Rate (%)	Capital City or Town	Last Inter Census Annual Urban Growth Rate (%)	Urban Population (%)	Land area (km)	Last Inter Census Annual Growth Rate Rural (%)
Melanesia	**8,641,883**						
Fiji Islands	847,793	0.5	Suva	1.5	51	18, 271	-.01
Papua New Guinea	6,744,955	2.1	Port Moresby	2.8	13	462, 824	2.7
Solomon Is.	549,574	2.7	Honiara	4.2	16	28, 370	2.5
Vanuatu	245,036	2.5	Port Vila	4.0	21	12, 190	2.2
New Caledonia	254,525	1.5	Noumea	2.5	63	18, 576	1.0
Polynesia	**663,795**						
Cook Islands	15,708	0.5	Rarotonga	3.0	72	237	-1.5
Niue	1,479	-2.3	Niue	-1.1	36	259	-2.3
Samoa	183,123	0.3	Apia	-0.6	21	2, 935	0.7
Tonga	103,365	0.3	Nuku'alofa	0.5	23	650	0.4
Tuvalu	11,149	0.5	Funafuti	1.4	47	26	-0.2
American Samoa	65,896	1.2	Pago Pago	2.4	50	57,291	1.7
Tokelau	1,165	-0.2	Nukunono	-	0	1,151	-4.6
Wallis and Futuna	13,256	-0.6	Mata-Utu	-	0	13,445	-2.1
French Polynesia	268,767	1.2	Papeete	0.7	51	259,706	1.8
Pitcairn Is.	66	-	-	-	-	-	**-**
Micronesia	**547,345**						
FSM	111,364	0.4	Kolonia	-2.2	22	701	**1.0**
Kiribati	100,835	1.8	South Tarawa	1.9	44	711	1.8
Marshall Is.	54,439	0.7	Majuro	1.6	68	181	1.3
Nauru	9,976	2.1	Yaren	-2.1	100	21	-
Palau	20,518	0.6	Koror	0.0	46	444	3.9
Guam	187,140	2.7	Hagatna	1.8	93	154,805	-1,4
Northern Mariana Is.	**63,072**	-0.1	Saipan	3.7	90	69,221	2.3

Source: Adapted from SPC Pacific Island Population Estimates and Projections, September, 2010.

Figure 1: Urban Share (%) by Pacific Subregion



The urbanisation of poverty

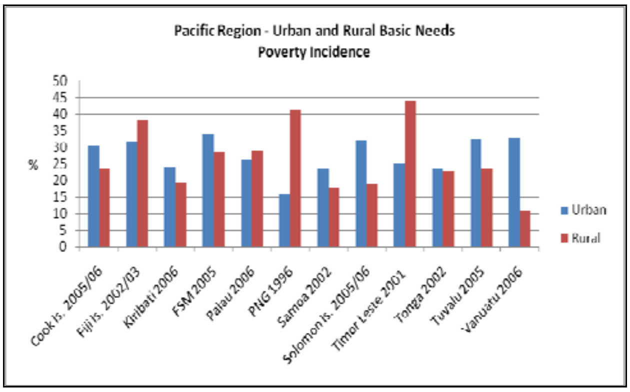
In the Pacific region, unlike other regions such as Asia where urbanisation corresponds with significant increases of GDP being produced in urban areas, urbanisation has occurred without sustained rates of economic growth.

Pacific urbanisation has been strongly led by population growth and migration. Generally, trends show that the urban share of poverty rises with increasing levels of urbanisation (UN Habitat, 2009). This is commonly referred to as the 'urbanisation of poverty', where there is a shift in the occurrence of poverty in rural areas to increasing concentrations of poverty in urban areas. With the urbanisation of poverty comes rising urban informality, especially in the land and housing markets and economic activity. This urbanisation of poverty and identification of the drivers causing such change was first documented in Fiji in 2004 (Government of Fiji, 2004).

The national poverty line estimates undertaken in PIC urban and rural areas are shown in Table 3. It shows that 9 out of the 12 PICs (where data is available) have greater urban populations below the Basic Needs Poverty Line (BNPL) than rural populations. Only four PICs - Timor Leste, Palau, Fiji and Kiribati – have greater rural populations below the BNPL than urban areas. Importantly, the proportion of those living below the BNPL in urban areas would be higher if PIC censuses were properly enumerated to reflect the actual built up urban areas.

This trend further reinforces the growing levels of urban poverty, which are inextricably linked to the urbanisation process in Pacific towns and cities.

Table 3: PIC Urban and Rural Basic Needs Poverty Incidence



Source: Park and Abbott, 2009, and Kiribati National Statistics Office - UNDP Pacific Centre, 2010

Conclusion

Ongoing urbanisation within weakened PIC economic settings has had a profound impact upon the precarious economic, social, and environmental fabric and well-being of Pacific towns and cities. The recent GFC has served to elevate the adverse symptoms of Pacific urbanisation, including poverty and growing settlements. However, continued lack of management of urbanisation in the Pacific region has dire consequences. The region's most urbanised city, Port Moresby, for example, is a city in decline, characterised by rising crime, violence, corruption, unemployment and growing levels of urban poverty. In 2010, Port Moresby was ranked as the world's third worst city in which to live (number 137), only marginally better placed than Algiers and Dhaka (equal 138), and Harare (140) (Economist, 2010).

Attempts to better manage the urbanisation process in the Pacific will continue to be constrained by:

- rising urban poverty levels;
- settlements outstripping planned suburbs;
- the permeation of rural norms and values in the urban setting;
- continued slow PIC economic growth per person accompanied by rising populations; and
- a reluctance by development partners, such as AusAID, to tackle major cross sector urban issues.

A major challenge for Pacific urbanisation is to turn the growing number of settlements into an opportunity, rather than being viewed as a problem.

The most recent national urbanisation policy in the Pacific region, the National Urbanisation Policy for PNG, 2010–2030, equates urbanisation with 'the modernisation of our villages, districts and towns', where rural and urban areas are to be provided with basic services and infrastructure in a planned setting (Dekena, 2010: 2). Urbanisation policy and programs can be a serious tool for national planning and development, providing a spatial dimension to economic plans and investment programs. In this context, mainstreaming planned and better managed urbanisation as a major development issue for action, including better aligned institutions, will be a major development challenge for all PICs in the next decade.

Note

[i] UN-Habitat defines sustainable cities as those that are environmentally safe, economically productive and socially inclusive. UN-Habitat, 2009. *Planning Sustainable Cities: the Global Report on Human Settlements*. Nairobi, Kenya.

References

Dekena, L., 2010, Keynote Address by the Hon. Minister for Lands and Physical Planning to the PNG National Urbanisation Policy Seminar, University of PNG, October 28, Port Moresby, PMG.

Economist, 2010, *Global Liveability Report,* Economist Intelligence Unit, January, London, UK.

El Sioufi, M. 2009, 'Escaping Slums: Confronting Global Urban Crisis', *Urban World*, UN-Habitat, 1: 4, October, Nairobi, Kenya.

Government of Fiji, 2004, 'Urban Policy Action Plan', Suva, Fiji.

Jones, P. 2010, 'Urban Poverty and the Global Economic Crisis — How Households Cope and Adapt', Paper presented to the seminar on the National Urbanisation Policy for PNG, 2010–2030, University of PNG, October 28, Port Moresby, PNG.

Jones, P. 2004, 'Managing Urban Development in the Pacific: Key Themes and Issues', in the *Australian Planner*, Journal of the Planning Institute of Australia,42, April, Canberra, Australia.

Muke, J. Mangi J. and Kimbu, R., 2001,'Poverty Alleviation in the Urban Settlements National Capital District', Japan International Cooperation Agency, July, Port Moresby, PNG.

Office of Urbanisation, 2010, *National Urbanisation Policy for Papua New Guinea, 2010*–2030, Independent State of Papua New Guinea, May, Port Moresby, PNG.

Parks W. and Abbott D. 2009. 'Protecting Pacific Island children and women during economic and food crises' Working Edition One for Advocacy, debate and guidance, UNICEF Pacific and UNDP Pacific Centre, Suva, Fiji.

Secretariat of the Pacific Community, 2010, Pacific Island Populations – Estimates and projections of demographic indicators for selected years. Noumea.

UN-Habitat, 2009, 'Planning Sustainable Cities: the Global Report on Human Settlements', Nairobi, Kenya.

UN-Habitat, 2008, 'Rapid Urban Sector Profile for Port Moresby, PNG,Nairobi, Kenya'.

UN-Habitat, 200, 'The Port Moresby Insecurity Diagnosis Report – Towards an Urban Crime Prevention Strategy', July, Nairobi, Kenya.

Reports

Implementing disability-inclusive development: Policy and Action Roundtable Report

Margaret Gadd, National Disability Services

Introduction

A one-day Policy and Action Roundtable was held at the Darwin Convention Centre on 17 September 2010, immediately following the Australian Disability and Development Consortium and the Australian National University's international conference 'Implementing Disability-Inclusive Development in the Pacific and Asia'.

This Conference, the second of its kind, was organised by the Development Studies Network at the Australian National University under the auspices of ADDC, in collaboration with key ADDC members including National Disability Services (NDS), the Australian Council for International Development (ACFID), the Australian Federation of Disability Organisations (AFDO) and People with Disabilities Australia (PWDA).

Approximately 70 conference delegates participated in the Roundtable, including key speakers, international visitors and representatives of Disabled Peoples' Organisations in Australia, Asia and the Pacific, AusAID's Disability Task Force, and a range of development agencies, disability service providers, donors and individual members of ADDC. Approximately two thirds of the participants were from developing countries in Asia and the Pacific, many with a lived experience of disability, and/or practical experience in addressing disability and disadvantage in their countries.

Aims and objectives

The Roundtable was convened to provide opportunity for individuals and organisations involved in disability and development to explore in more detail the key themes of the conference, and to discuss, network and exchange information in relation to effective disability-inclusive development across the region, specifically identifying common features of good practice.

The Roundtable also aimed to develop recommendations for building on current disability-inclusive development practice in Asia and the Pacific.

Discussion

The most significant issues to emerge during the course of discussion included:

1. *What is 'disability-inclusive development'?*

Despite general consensus on the broad concepts of 'disability' and 'development', it became apparent that a common understanding of what constitutes 'disability-inclusive development' cannot be assumed.

The diversity of Roundtable participants provided evidence of the wide range of stakeholders, partnerships, interests and activities which exist under the banner of 'disability-inclusive development', and the consequent spectrum of ideas which surround it.

The Roundtable sought to identify features common to a variety of concepts and definitions. Broad consensus was reached on the following:

- disability-inclusive development is both a process and an outcome and operates within a twin-track approach — i.e. mainstream and disability-specific;
- disability-inclusive development involves activities and programs aimed at changing social systems and structures to ensure that people with disability have equal rights and access to all aspects of social, economic and political life within their families and communities;

- disability-inclusive development involves a diversity of stakeholders and partnerships and a wide range of participants — including DPOs, INGOs, regional NGOs, governments, service providers, human rights institutes, CBR practitioners, major contractors, churches, self-help groups and individuals, families and communities;
- a human rights approach is fundamental and integral to disability-inclusive development;
- government engagement and action is essential; and
- disability-inclusive development is an ongoing process of continual improvement and learning.

2. *What constitutes 'good practice' in disability-inclusive development?*

Representatives from Papua New Guinea, Fiji, Cambodia, Bangladesh, Vietnam, Tuvalu, Laos and Vanuatu presented case studies and examples of activities which they deemed to have been effective in improving the lives of people with disability in their countries.

These examples clearly demonstrated that common challenges exist in all developing countries in relation to disability and disadvantage. It also became readily apparent that, within a broad range of cultures and contexts, different frameworks for action are inevitable and appropriate. Importantly, however, regardless of local variations in practice, many common features could be identified in the most effective development programs. The following features, common to many of the case studies presented, were agreed to be essential to 'good practice' in disability-inclusive development:

- active inclusion and involvement of people with disability (or DPO advocates) at every stage of the program or activity;
- practical actions based on a human rights philosophy and approach;
- equality in partnerships (eg with international NGOs, service providers etc);
- assistance from donors and development partners based on consultation and agreed needs;
- strong leadership and good governance;
- inclusive community involvement;
- accountability; and
- sustainability.

3. *The critical importance of government engagement*

It was agreed that national governments are responsible for developing, promoting and implementing (or enabling implementation) of their political, economic and social policy. It was further agreed that they must also commit to, and meet their obligations, with regard to international laws and conventions which they have ratified and/or endorsed. It follows, therefore, that they also have a primary responsibility to resource and fund programs to ensure that laws are upheld, obligations are met and policy goals are achieved.

Roundtable participants considered that there is need for greater clarity and awareness-raising within both government and civil society in relation to the role and responsibility of governments for the rights and needs of people with disability. Representatives from Papua New Guinea stressed the importance of finding and supporting government 'champions', and maintained that this requires strategic planning on the part of DPOs to develop and maintain links with Ministers and senior officials.

It was agreed that DPOs need direct, recurrent funding for operational activities, as well as funding support for program activities. The long term goal must be to achieve core funding through national budget processes, while also having the flexibility to seek funding support for specific activities from governments and other independent sources.

4. *Developing a business model of governance*

The transition from a 'welfare-based' or 'charity' model of disability to a human rights-based approach which aims for full social inclusion necessitates that DPOs move towards an inclusive business model of governance and practice. Active, strategic engagement with government and the wider community requires, among other things, strong leadership, sound management of resources, regular planning and evaluation.

The Pacific Disability Forum (PDF) and Asia-Pacific Development Centre on Disability (APCD) were cited as models of disabled peoples' organisations with the capacity to interact with national governments, international organisations and commercial entities using a business approach. For example, a representative from APCD described how APCD has introduced a program of fee-based disability awareness training in the corporate sector in Thailand. This program not only educates business leaders and employers about disability and gains the support of this powerful sector of society, but at the same time further builds the capacity, skills and confidence of APCD trainers and other staff.

It was agreed that many DPOs still need support from partners and international donors in relation to capacity building. AusAID representatives emphasised that this remains a priority of the Australian Government's *Development for All* strategy. *(See p.19 of the Strategy: 'An early and strong focus on assisting DPOs to strengthen their capacity is critical in establishing the foundation for disability-inclusive development. Development of sound leadership, management and organizational capabilities, in addition to effective advocacy skills (are) critical areas for support'*).

AusAID also strongly encouraged DPOs to ask questions, challenge assumptions and expectations, and hold donors accountable.

5. *Inter-regional cooperation between DPOs and other sectors*

Throughout the day's proceedings, there were many reminders of the need for ongoing communication and support between DPOs across the region. Participants strongly agreed that opportunities for sharing and learning must be maintained and extended. The example of the Pacific Disability Forum which brings together the interests of DPOs across many Pacific Island countries was recognised and applauded.

The need for cooperation and intersection with other sectors was also emphasised, particularly in relation to other issues of vulnerability — eg poverty, gender, age, dislocation etc. It was noted that much can be learned from the experience of other groups who have struggled for equality and recognition.

It was also highlighted by a number of participants that DPOs have an important role in mainstream development. The rights and needs of people with disability must be recognised in all development activity — eg health, education, water and sanitation — and DPOs can contribute expert advice and support in these areas.

6. *Measurement and evaluation*

Data collection and research were identified as ongoing essential needs. Participants were aware that a second Roundtable was being held concurrently to discuss research, and that a separate report and recommendations would be prepared.

7. *Other issues raised during discussion*

While not discussed in detail during the Roundtable, the following matters were noted as significant items for future forums, and for follow-up within individual countries:

- inclusive education should be regarded as a priority for future development funding;
- the needs of people with hidden disabilities and mental illness should be recognised and addressed more actively;
- it is critical to encourage and mentor young people with disability in order to plan for the future and overcome risks associated with entrenched structures and personnel. A suggestion was made to consider the establishment of a Youth Committee within the Pacific Disability Forum, in partnership with Australia and New Zealand;
- DPOs should work closely with community leaders and raise awareness of disability issues within local communities.

Recommendations for achieving best practice

Key recommendations for the way forward were agreed, as follow:

- continue building on current strengths, and strengthen knowledge sharing and experience across countries and regions;
- continue discussing the concept of ‘disability-inclusive development’ — what it means and how it can be achieved in practice;
- explore notions of ‘quality’ in disability-inclusive development — and recognise the importance of both quality and quantity;
- engage strategically with those who have the power to make changes in order to increase the credibility of DPOs and respect for disability issues;
- improve outcomes by including clear, measurable disability-inclusive objectives in mainstream and disability-specific planning — also specific timeframes for projects;
- develop and implement flexible funding models, for example, by recognising DPOs as NGOs and funding accordingly; and
- combine a business focus with a human rights approach and work at all times towards continuous improvement in disability-inclusive development.

Strengthening research on disability inclusive development in the Asia Pacific region

Report of the Research Roundtable

Kirsty Thompson, Fareen Walji and Joanne Webber, CBM Australia

The focus of the one day research roundtable was to discuss new and innovative research in the fields of disability-inclusive development, along with the elaboration of research gaps, capacity and priorities for future research in this field. There were approximately 60 participants including grass roots and academic researchers from Asia and the Pacific; academic researchers from Australia relevant to disability and/or development; representatives of Disabled Peoples' Organisations from the Pacific and Asia regions; and representatives from donor, disability and international development organisations.

The roundtable facilitators were Kirsty Thompson, Fareen Walji and Joanne Webber. In addition five researchers were selected and funded to support the roundtable facilitation based on their expertise in disability and development. These researchers all live and work within developing countries with three having a disability, further enhancing the strength of the day through personal experiences. These researchers were:

> **Dr. Maya Thomas** from India who has been working with the Asia Pacific Development Centre (APCD) and contributed her expertise in Community Based Rehabilitation and disability-inclusive development.
>
> *Dr Bishnu Maya Dhungana* from Oxfam GB in Nepal who shared her research expertise in the challenges faced by women with disability in developing countries. She offered a strong knowledge of the profound impact gender, cultural and social practices have on the experience of disability.
>
> *Rex Bernardo*, the director for research and development at Mabini College in the Philippines who shared his passion about disability empowerment and inclusion in developing countries with a particular focus on capacity building of DPOs.
>
> *Sainimili Tawake* who works as a Project Officer for the Fiji National Council for Disabled Persons (FNCDP). She offered grass roots expertise and a passion in those most marginalised within the disability population including women and people living with mental illness.
>
> *Dr Nafisa Lira Huq* from Bangladesh who shared her varied expertise in research in adolescents, youth, sex workers and pregnant women.

The roundtable provided opportunity for individuals, DPOs and academics from Australian and Asia Pacific based institutions to contribute to the identification of priorities for research in disability-inclusive development and to the development of a report outlining the regional research agenda. CBM Australia managed a research team who led an investigation in disability-inclusive development in Asia and the Pacific. A literature review and series of semi structured key informant interviews were compiled to provide an up to date analysis of the status of research. Evidence to date was shared at the roundtable with further input collated on the day. The final desk review was completed on September 30, 2010. This work was a collaborative effort through the University of Sydney and RMIT University led by Professor Gwynnyth Llewellyn and Dr Jonathan Makuwira.

Summary of findings from the desk review

Given that the focus throughout the project was on research gaps, priorities and capacity building requirements, it was particularly heartening to encounter sustained commitment to the view that research is critically important for the disability-inclusive development field. This emerged from the widespread view that the many different perspectives on the lives of people with disability often come from anecdote, or hearsay or, all too frequently, only from those able to speak out rather than from any systematic and structured approach to understanding the lives of people with disability and their particular environments. This gives rise to an even larger concern, the scarcity of robust information about large and pressing issues such as the barriers that prevent people with disability and their organisations from participating in development and the barriers preventing development activities from becoming disability inclusive. Given the diversity in disability, and the changes in societies that are affecting the lives of people with disability in ways that are poorly understood, it is particularly worrying that there is very little disability-inclusive research.

Research priorities

Within this context, five recurring issues emerged that are regarded as critically important in considering research priorities. These are:

- the lived experience of people with disability in all its richness and diversity;
- the exclusion of people with disability from 'mainstream' opportunities, facilities and services of the societies in which they live;
- prevalence data that are able to illustrate the diversity of disability on many dimensions including but not limited to culture, gender, impairment, ethnicity, age and place of residence;
- the identification of regularly used terms such as disability, inclusion, development and disability-inclusive development and clarifying how these are understood in particular cultural and national contexts; and

- the effectiveness of what is being done, whether this be policy development and implementation, or programs and their operations, or DPO representation and advocacy.

Building research capacity

The desk review findings suggest that research in disability-inclusive development in Asia and the Pacific region is in its infancy. The difficulty identifying researchers, over and above the problems of finding out about research, is a barrier to developing the field. If researchers and supporters of research cannot locate others with similar topical interests and complementary skills, then each are limited to their own personal networks and to developing their own research. In an emerging field the potential for growth is more likely to be maximised if the stakeholders are connected.

The following five strategies emerged as foundational to building research capacity in disability-inclusive development in Asia and the Pacific region:

- building and maintaining partnerships and relationships that foster, enhance and sustain research implementation and outcomes;
- embedding resources in all program funding for information gathering, evaluation and research activities, and documenting and sharing the knowledge gained;
- information sharing;
- making disability core business in all aspects of development; and
- asserting and operationalising ‘nothing about us without us’ as the fundamental principle underpinning the research process from beginning to end.

Evaluation and recommendations

The overall satisfaction rating of this roundtable was 8/10 with participants expressing the following benefits for the research roundtable: Strong participatory approaches; valuable opportunity for sharing experiences and research ideas; and a good opportunity to meet with other researchers and DPOs from developing countries. Participants were motivated to:

- build local capacity and research partnerships;
- conduct mapping of local unpublished informal research;
- identify and share grey literature; and
- source funding for further research in disability-inclusive development.

Recommendations were to enhance collaborative research partnerships with mainstream NGOs, DPOs and local and international research universities. There was keen interest in future research roundtables with the desire to have annual capacity for similar disability-inclusive development research gatherings.

The desk review into disability-inclusive development research in Asia and the Pacific will be available on the website of the Australian Disability and Development Consortium www.addc.org.au.

Report on UNDPI/NGO Conference 2010: Effective advocacy, positive outcomes

Sam Byfield, Vision 2020 Australia

Introduction

From 30 August–1 September 2010 the United Nations Department of Public Information/Non-Government Organisation Conference 'Advance Global Health — Achieve the MDGs', was held in Melbourne, attended by over 1700 participants from more than 230 NGOs. This was only the third time in its 63 year history that the conference had been held outside New York. The conference provided an excellent opportunity for NGOs from Australia, Asia and the Pacific to engage with the UN and raise awareness about public health issues.

Efforts by the disability, development and eye health sectors ensured that representation from these sectors was high on the agenda of the UNDPI/NGO conference. This paper provides an overview of steps taken to achieve this inclusion and provides some thoughts on how advocacy can be used to achieve better outcomes for people with disability.

The Australian Council for International Development working group

The Australian Council for International Development (ACFID) convened a working group to provide initial consultations once it was known that the conference was going to be held in Melbourne. A number of representatives from this sector participated in the working group, which contributed to shaping the conference from an early stage. ACFID played a lead role in ensuring disparate elements of the conference came together successfully. Agencies seeking to have their views heard at the conference engaged closely with ACFID.

Each year, the UNDPI/NGO conference is run primarily by volunteers from civil society in New York and the host country — this time Australia. Volunteers were sought to participate in committees to oversee elements of the conference including workshops, exhibits and roundtables. The workshops committee was responsible for assessing and organising 54–90 minute workshops that constituted a large part of the conference. I was involved in workshop planning from an early stage, partly because of a desire to be a part of an interesting and important event, and partly because this was a good way to ensure the interests of Vision 2020 Australia and the broader disability and development sector. Several months before the conference commenced I was offered the role of co-chair of this committee.

Focus of the workshops

A selection process was undertaken to determine the foci of 54 workshops. Two workshop applications were submitted — for disability and development, and eye care sectors. The first focused on the broader disability and development agenda, including how best to undertake disability inclusive development and the role of disabled people's organisations in Asia and the Pacific. Participants included Kirsty Thompson from Christian Blind Mission (CBM) Australia, Seta Macanawai from the Pacific Disability Forum, Jennifer Gersbeck from Vision 2020 Australia, Daniel Stubbs from the Australia Pacific Islands Disability Support, and Pauline Kleinitz from the CBM-Nossal Institute Partnership for Disability Inclusive Development.

The second workshop focused on the relationship between vision impairment and the Millennium Development Goals (MDGs) and the leadership role Australia has taken under the Avoidable Blindness Initiative. Speakers in this workshop included former parliamentarian and chair of Vision 2020 Australia, the Hon. Barry Jones AO, Professor Hugh Taylor AC from the University of Melbourne, Brian Doolan from the Fred Hollows Foundation, Peter Ackland from the International Agency for the Prevention of Blindness, and Amanda Davis from the International Centre for Eyecare Education.

In what was a highly competitive application process, both these workshops were accepted. The relevance of the workshop proposals to the broader themes of the conference and high calibre of the proposed speakers were central to these workshops being accepted.

Workshop attendance and lessons learnt

Having the workshops accepted was only half the work. We still had to ensure that people attended. Both workshops were well attended, particularly the disability workshop which had over 60 attendees, mostly from outside the disability and development sector. One lesson from this process was the power of marketing. In order to attract people to attend, we developed and printed 100 flyers and distributed these throughout the conference venue. This was useful in raising awareness as I overheard conference attendees discussing a workshop before it took place.

Another way to ensure our messages were heard in conference proceedings was to run an exhibit. Vision 2020 Australia applied successfully to manage an exhibit, which provided an opportunity for representatives from the eye health sector to raise awareness, discuss key issues and disseminate promotional material. Other exhibitors included AusAID, the UNDPI and NGOs from Australia and the region. The steady stream of people ensured that eye health and disability issues were firmly on the agenda and attendees saw these issues as important and credible.

Advocacy and awareness raising

One of the most important elements of the conference for advocacy and awareness-raising was the outcomes statement — a summary of proceedings and a commitment on behalf of participants to improve global public health — developed prior to and during the conference. In the lead up to the conference, a draft communiqué was circulated for feedback. Vision 2020 Australia developed a position paper specifically asking for inclusion of eye health in the communiqué within the context of disability. The Australian Disability and Development Consortium provided a position statement which outlined the importance of disability inclusion in development programs.

A meeting was held at the conference for interested parties to request amendments/inclusions to the communiqué. A wide variety of speakers participated, including a lobbyist from the Universal Esperanto Association who argued that if poverty is to be eliminated we all need to start speaking Esperanto. Peter Ackland from the International Agency for the Prevention of Blindness requested the addition of disability to the communiqué. As a consequence of these efforts, the final communiqué contained several references to disability as 'a significant health challenge targeted by the MDGs'.

The two position statements, although having slightly different foci, were still consistent. This is an important element of successful advocacy — agencies from the same sector might have different views on some issues, yet it's important to determine areas of shared interest and ensure that stakeholders don't contradict each other in key messages. This ensures that an approach is strengthened rather than undermined and that credibility is maintained.

Summary and the need for ongoing advocacy

Ongoing, effective advocacy in this area is vital. The disability and development sector needs to have a strong and cohesive presence at forums such as the UNDPI/NGO Conference and needs to emphasise that the rights and needs of people with disability have a central role in achieving the MDGs. Tying disability into this broader discourse is important and is a case of 'talking the talk' and utilising a multi-pronged approach. This includes:

- liaising directly with parliamentarians and government officials;
- attending and speaking at conferences;
- influencing processes involving the United Nations and other major global powers;
- raising awareness through publications; and
- developing effective partnerships with government departments.

Although the UNDPI/NGO Conference exemplified several elements of effective advocacy much work is still needed to ensure enhanced awareness of the vital importance of the needs and rights of people with disability in developing countries.

Shadow reporting for CPRD Country Reports

Therese Sands, People with Disability Australia

When a country ratifies the CPRD they have initially two years to develop a baseline report that goes to the UN. It is then reviewed by the CPRD team who provide concluding observations or recommendations back to the country. The country is then meant to go away and look at how they can implement those recommendations. Four years later, they send another report back to the UN. What accompanies this second report is a report from the NGO sector — known as the shadow report. In this case, I would strongly stress the role of DPOs. They have the opportunity to put together a report from their perspectives. This report also goes to the UN. The UN then considers both reports together when it provides its recommendations back to the government.

So the shadow report, or alternative report, is a really critical advocacy tool, or an advocacy process, in terms of getting issues that may not be covered by the government report, onto the agenda. It is an opportunity for the DPOs to influence what the UN is telling countries they must do. So Australia is in the process of that now.

The Australian situation

In Australia, we ratified in 2008 and our government report was due to be presented to the UN by the end of 2010. In October 2011, they will be reporting to the UN Committee, depending on the schedule of the Committee. So the NGO sector and the DPOs had to work quickly to put in place this parallel process.

We needed to bring together DPOs in Australia, people who work in advocacy organisations and people with disability who are particularly marginalised and who may not be members of DPOs. These include those who live in segregated institutions; people who may be in the criminal justice system or in prisons; or who live in boarding houses. As we didn’t have the time to reach these people individually, we relied on peak organisations, advocacy organisations and DPOs.

We formed a group made up of Disability Australia, Queensland Advocacies Incorporated and legal centres that work around discrimination law in Australia; the Disability Advocacy Network, which is a network of the advocacy organisations around Australia; the Australian Disability Rights Network, which comprises community legal centres; and the Disability Studies and Research Centre, which does a lot of participatory research.

In looking at our methodology, we had one year to put the report together and no funding. We were very fortunate to have contact with DLA’s Phillip Fox, a law firm, who offered to provide us with pro bono support. They also provided pro bono support for Bangladesh to develop their shadow report. We also got some funding from the Government through the Department of Family Housing, Community Services and Indigenous Affairs.

In the past, DPOs have had to push their way in to make sure their voices were heard. The ratification of CRPD, has changed this situation and human rights organisations are coming to us, but we know that for many DPOs, particularly at the local and state levels, this was their first opportunity to be involved in shadow reporting on human rights mechanisms. It was looking at disability from a human rights perspective rather than a welfare perspective.

From welfare to a human rights perspective

To ensure these organisations were aware of the shift from welfare to human rights we developed background information on the CRPD and the UN reporting process. We also developed a work book to use throughout our consultations. The funding we received meant that we could undertake consultations in each capital city.

In relation to Article 32, International Cooperation, we had a brief consultation session with the Australian Disability and Development Consortium, so that we would get their expertise around how international cooperation is working in terms of their views of AUSAID programming and the status of development in Australia.

So we are now at the point where we have a draft report and the project group is now looking at the draft report, ready to provide comment back to finalise that report. We are also hoping to send a delegation to Geneva to lobby the committee when the UN is reviewing the Australian Government’s report.

Using the shadow report

The NGO sector, particularly DPOs, can use their shadow report, and the concluding observations, to guide them in the best strategic priorities in working with government, because government will get recommendations and then the DPO can use those to plan their strategic priorities. So they are very, very important, and can also be used to hold government to account in terms of saying, ‘Well, the UN said that you were meant to do this, what are you doing about that action?’ And they can offer to assist in working together to progress those recommended actions.

Women with Disabilities: Some statistics

USAID Background Report

General statistics

- According to WHO 10 per cent of men, women and children worldwide live with some form of disability.
- Approximately 300 million women and girls around the world have an intellectual, mental, sensory, and/or physical disability.
- Globally, women make up three-fourths of the disabled people in low and middle income countries. Between 65 and 70 per cent of these women live in rural areas.
- In OECD countries, statistics consistently identify between 12 and 20 per cent of the population as disabled. In most OECD countries, women report higher incidence of disability than men.
- The ILO reports that women are at increased risk of becoming disabled during their lifetimes due to neglect in health care, poor workforce conditions, and/or due to gender-based violence.
- The World Bank estimated that two per cent of the world's poorest people have some kind of disability, and that they tend to be regarded in their own communities as the most disadvantaged. Women with disabilities are recognised to be double disadvantaged, experiencing exclusion on account o both their gender and their disability.
- The World Bank estimates that one in five peopled living on less than $1 a day have a disability.
- The ILO states that women with disabilities are at increased risk of being sicker, poorer, and more socially isolated than either men with disabilities or non-disabled women.
- The UN reports that the combination of male preference in many cultures and the universal devaluation of disability can be deadly for disabled females.

Employment

- According to the UN, only 25 per cent of women with disabilities are in the workforce worldwide.
- According to the International Disability forum in Geneva, 75 per cent of women with disabilities worldwide and up to 100 per cent in some developing countries are excluded from the workforce — though the majority contribute significantly to their families through cooking, cleaning and caring for children and relatives.
- Women with disabilities are twice as unlikely to find work as disabled men.
- United States statistics show that men with disabilities earn 65 per cent more than women with disabilities.
- According to the World Bank, disability-based discrimination in the employment context constitutes one of the most pervasive and insidious forms of discrimination faced by persons with disabilities in many societies.

Education and literacy

- UNDP reports that the literacy rate for people with disabilities is three per cent, with the literacy rate for women and girls with disabilities is as low as one per cent.
- UNICEF estimates that 98 per cent of children with disabilities in developing countries do NOT attend school.
- Perkins International estimates that there are six million children who are blind or visually impaired throughout the world. Only 10 per cent of these children attend school. Girls with disabilities are less likely to attend school compared to boys with disabilities.
- UNICEF estimates that approximately 30 per cent of the world's street children have a disability.

Health and nutrition

- In developing countries, there is a high reported mortality rate for girls and women with disabilities due to neglect, lack of medical care, and less access to food or related resources.
- A UNICEF study in Nepal reports that the survival rate for boy chidren, several years after they had had polio, is twice that for girls despite the fact that polio affects and equal number of boys and girls.
- UNESCO states that 500,000 children every year lose some part of their vision due to Vitamin A deficiency. Perkins International estimates that 60 per cent of children who lose their vision die within a year of going blind.
- UNESCO states that 41 million babies born each year risk developing an intellectual disability due to insufficient iodine in their mothers' diets.
- There are few rehabilitation services available to men and women with disabilities. UNICEF states that only three per cent of individuals receive the rehabilitation support that they need.

HIV/AIDS

- World Bank states that women with disabilities face unique challenges in preventing HIV infection, due to the heightened risk of gender-based violence, lack of access to reproductive health care services, and low awareness of mother-to-child HIV transmission.
- A World Bank survey of disabled persons organisations, shows that 87 per cent of the organisations surveyed reported that HIV/AIDS is of immediate concern to the disabled populations they serve.
- The folk belief that individuals with sexually transmitted diseases (including HIV/AIDS) can rid themselves of the infection if they have intercourse with a virgin poses a particular risk for disabled children due to the mistaken belief that individuals with a disability are sexually inactive.

Gender-based violence

- A World Bank study showed that women with disabilities are more likely to be victims of violence or rape than non disabled women, and they are less likely to be able to obtain police intervention, legal protection, or prophylactic care.
- A 2004 survey in Orissa, India, found that virtually all the women and girls with disabilities were beaten at home, 25 per cent of women with intellectual disabilities had been rapid, and six per cent of women with disabilities had been forcibly sterilised.

- OECD studies suggest that 39–68 per cent of girls and 16–30 per cent of boys with intellectual or developmental disabilities will be sexually abused before their 18th birthday.

Human trafficking

- Women and girls with disabilities are also at risk from being trafficked and forced into prostitution though they are rarely included or considered in anti-trafficking programmes.
- A UNICEF report in Thailand states that proprietors of houses of prostitution have specifically sought out deaf girl children and adolescents, with the idea that such young people will be less able to communicate their distress or find their way back to their homes in a world where neither their customers nor their employers or fellow sex workers are able to communicate with them.
- A UNICEF study in Taiwan found that the proportion of child prostitutes who had mild developmental disabilities was six times greater than what might be expected from the incidence in the general population.

Reference

http://www.usaid.gov/our_work/cross-cutting_programs/wid/gender/wwd_statistics.html.

Violence against women with disabilities

The International Network of Women with Disabilities (INWWD)

The following report includes key extracts from a larger document produced in October 2010 by the International Network of Women with Disabilities. The full document based on extensive and intensive research and with a full bibliography is available on www.wwda.org.au/viol2006.htm.

Gender-based violence against women is a crime and a human rights violation that occurs, often repeatedly, in the lives of a great number of women around the world. Although the forms of violence experienced may differ depending on culture or socioeconomic standing, there are aspects of that violence that are universal. Gender-based violence is rooted in the lack of equality between men and women, and frequently takes place at home, within the family circle. Societal tolerance for gender-based violence and the privacy of the act of violence when it takes place within the home can make it invisible or difficult to detect.

As seen in the Declaration of Violence against Women, gender-based violence includes a wide range of abusive actions, including genital mutilation; physical and emotional abuse; and economic exploitation. According to the World Organisation Against Torture, rape and sexual abuse, genital mutilation, incest, forced abortion, honour killings, dowry-related violence, forced marriages, human trafficking and forced prostitution should all be considered forms of torture.[1]

Disability-based violence

Studies show that persons with disabilities are victims of abuse on a far greater scale than persons without disabilities.[2] One factor behind the increased incidence of violence against persons with disabilities is the stigma associated with disability; persons with disabilities are often considered by society to be 'not completely human and of less value ... The absence of representations of their identity favours the perception that one can abuse them without remorse or conscience'.[3] Some societies may believe that the disability is a punishment from God or that the person with the disability may infect others with the disability. Others may see a person with a disability as an object for charity or pity, rather than as a person deserving equal rights.

The medical context is a particular source of abuses practiced against persons with disabilities.[4] According to the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, one of the purposes in the definition of torture is 'for reasons based on discrimination of any kind' and noted that acts of serious discrimination and violence against persons with disabilities can be masked by 'good intentions' of medical professionals. Medical treatments of an intrusive and irreversible nature enforced or administered without the free and informed consent of the person concerned, that lack a therapeutic purpose or are aimed at correcting or alleviating a disability, may constitute torture or ill-treatment of persons with disabilities. These kinds of actions include: forced abortion and sterilisation, forced psychiatric interventions, involuntary commitment to institutions, and forced or 'unmodified' electroshock (electro-convulsive therapy or ECT).[5] Deprivation of the legal capacity to make one's own decisions facilitates coerced treatments and violence of all kinds, and may constitute torture and ill-treatment in itself, as it can amount to a denial of full personhood.[6] Such a profound form of discrimination can cause severe suffering.

The intersection between disability and gender-based violence

Some forms of violence against women with disabilities have not been visible as gender-based violence because of the heightened discrimination based on disability. Various reports document the fact that women (in general) are more likely to suffer abuse and maltreatment than men, but evidence from women with disabilities themselves suggests that violence against them differs in significant ways from violence against other women.

The incidence of maltreatment and abuse of women with disabilities far exceeds that of women without disabilities.[7] The available data, though scarce, also shows that there is a higher rate of violence against women with disabilities than against men with disabilities.[8] Violence against women and girls with disabilities is not just a subset of gender-based violence: it is an intersectional category dealing with gender-based and disability-based violence. The confluence of these two factors results in an extremely high risk of violence against women with disabilities.

In one study, 40 per cent of the 245 women with disabilities interviewed had experienced abuse — 12 per cent of them had been raped. However, less than half of these incidents were reported. Another study found that 25 of 31 interviewed women with disabilities reported abuse of some kind (emotional, sexual or physical).[9] Women with disabilities experience a wider range of violence: by personal attendants (emotional, physical and sexual abuse) and by health care providers (emotional and sexual abuse), as well as higher rates of emotional abuse both by strangers and other family members.[10]

In other words, women with disabilities experience forms of abuse that women without disabilities do not.[11] In addition to the overt acts of gender-based violence described above, there are more subtle ones which stem from attitudinal discrimination against person with disabilities. Lack of respect for their personhood and discrimination against persons on the basis of their physical or mental disabilities is an act of violence in itself, and generates intense frustration in the person who experiences the discrimination. When we factor in discrimination on the grounds of gender, the extent of discrimination and violence perpetrated against women with disabilities is unacceptable and intolerable.

Violence against women with disabilities is part of the larger issue of violence against persons with disabilities in general and includes violence accomplished by physical force, legal compulsion, economic coercion, intimidation, psychological manipulation, deception, and misinformation, and in which absence of free and informed consent is a key analytical component. Violence may include omissions, like deliberate neglect or lack of respect, as well as overt acts that harm a person's physical or mental integrity.

The following actions and attitudes constitute violence against women with disabilities[12]:

- forced isolation, confinement, and being hidden in the family home;
- forced and coerced administration of psychotropic drugs or putting drugs in the food;
- forced and coerced institutionalisation;
- restraint and isolation in institutions;
- creating pretextual situations to make the woman appear violent or incompetent in order to justify institutionalisation and deprivation of legal capacity;
- labelling anger and self-assertion by women as behaviour that is 'mentally ill and dangerous' (especially if the woman has been previously institutionalised);
- withholding medication that the person uses voluntarily, medical and mobility aids, or communication equipments;
- denial of necessities and purposeful neglect;
- threats to neglect children or pets;
- verbal abuse and ridicule;
- physical abuse or threat of it;
- being left in physical discomfort or embarrassing situations for long periods of time;
- threats of abandonment;
- violations of privacy;
- being ignored;
- financial abuse;
- restraint, strip searches, and solitary confinement that replicate the trauma of rape;
- rape by staff and other inmates/residents of institutions;
- forced abortion; and
- forced sterilisation.

Some forms of violence against women with disabilities are not immediately visible as violence because they are in fact legal and accepted in society. This is particularly true of forced psychiatric interventions and institutionalisation. These acts of violence are done under the legal authority of the state, and in pursuance of wrong and discriminatory state policy, and there is no possibility of redress, emphasising the message of all violence that tells the victim she is powerless.

There is anecdotal evidence from women with disabilities that, relative to men with disabilities, women with disabilities have less access to qualified medical care and rehabilitation, are provided with less expensive medications, assistive devises and other treatments, and have less access to social supports, higher education and opportunities for employment. A consequence of this inequity is that women with disabilities are deprived of their right to social inclusion and are often forced to live in poverty.

Women with disabilities have also reported experiencing abuse of longer duration and feeling as though they had fewer alternatives for escaping or ending the abuse.[13] Indeed, while women with disabilities share the barriers that any other woman has to face to escape or end violence (emotional and financial dependency on the abuser, unwillingness to be stigmatised, worries about being a single parent or fear of losing contact with children, concerns that they will not be believed or helped when they disclose abuse, reluctance to take any action that will escalate the violence), there are other barriers that specifically affect women with disabilities:

- increased dependence (physical, financial or both) on the abuser for care;
- difficulty in making contact with refuges or other intervention services;
- lack of access to information about available services;
- difficulties in accessing transportation;
- fear of being institutionalised; and
- fear they will not be believed, either because some professionals do not recognise the capacity of women with disabilities for sexual and intimate relationships or because professionals may fail to understand and identify forms of abuse they experience and instead shift the focus to the impairment, thereby obscuring the abuse.

When the violence is perpetrated by personal assistants, family members and/or friends, it is often considered to be a problem that can be addressed by the social service system rather than considered to be a crime that should be addressed by the police and/or the criminal justice system.

Why women with disability are abused

Violence against women with disabilities occurs primarily as a result of attitudes towards women in patriarchal society coupled with vulnerability from the conditions that result from the disability itself, such as being physically less capable of defending themselves; having difficulty reporting maltreatment due to the lack of accessible forms of communication; lower self-esteem due to not being seen as a woman but only as a person with a disability, or even worse — only as her disability; and a greater amount of dependence on other people for care. The long-lasting effects of electroshock and some psychiatric drugs can impair women's ability to defend themselves against violence and abuse and the legalisation of some forms of violence (such as institutionalisation, solitary confinement and restraint, forced drugging and electroshock, forced abortion and sterilisation) so that there is little or no possibility of effective self-defense.

Girls, older women, and indigenous women with disabilities face additional barriers and violence as a result of even more complex intersectional forms of discrimination.

In spite of the severity of the discrimination, the strength of the societal prejudice against women with disabilities, and the evidence of their own experiences, violence against women with disabilities is not recognised. It is hidden and ignored, and this fact increases their exposure to violence. The following factors contribute to this invisibility:

- referring to 'people' with a disability rather than 'men and women' with a disability contributes to a gender-neutral concept of disability that ignores women with disabilities, renders their needs invisible, and contributes to their isolation;
- lack of a broad definition of violence which embodies all forms of violence that women with disabilities suffer;
- some forms of violence against women with disabilities are permitted by law and carried out under the authority of the state;
- professionals, relatives, friends, etc. are unable to discern circumstances resulting from violence against women with disabilities because they think they are circumstances 'inherent' to their disability;
- researchers, policy-makers, etc. rarely identify situations, such as physical abandonment or psychological cruelty as maltreatment;
- lack of credibility accorded to women who require assistive communication or reasonable accommodation in communication;
- it is easy for others to say a woman is 'making it up', particularly if she has already been labelled with a psychiatric diagnosis or an intellectual disability and
- the difficulty for a progressive society to admit that a woman with a disability has been the object of violence or abuse.

Conclusions

Many women with disabilities see themselves as victims of maltreatment and abuse, while society ignores the problem. However, some women with disabilities may not see themselves as victims of violence because they consider their situations habitual and associated with disability. In some situations society refuses to recognise that certain acts constitute violence, and the women who experience them may or may not consider themselves as victims. This is particularly true with respect to acts authorised under domestic law, such as forced psychiatric interventions with mind-altering drugs, electroshock or psychosurgery, institutionalisation, restraints and isolation, which are practiced primarily on women with psychosocial disabilities and women with intellectual disabilities.

Violence against women with disabilities shares common characteristics with violence against women in general, but has unique dimensions as well. Being a women and having a disability increases the likelihood of experiencing violence as compared to the risk for women in general. Women with sensory, learning, and communicative disabilities are particularly vulnerable to suffering abuse and violence.

Women labelled with psychosocial disabilities are likely to be silenced and ignored when speaking out or attempting to defend themselves, particularly when the violence is authorised by law or committed in a context where the woman is deprived of her legal capacity and/or freedom. These women and the forms of violence practiced against them are also likely to be ignored in studies of violence against women with disabilities.

Not having opportunities to function in traditional female roles, as well as having either conformity or resistance to traditional female roles labelled as a psychosocial disability, contributes to lower self-esteem and increases vulnerability, which can be contributing factors to becoming targets of violence.

Professionals who work with women who have experienced abuse often do not recognise that women with disabilities are in the same situations, either because they do not have the information or because they do not recognise acts they believe to be associated with disability, including forced institutionalisation and forced interventions, as acts of violence. Depending on others to cope in daily life increases the risk of being targets of violent actions. This risk can be reduced when proper training is provided to the people who are providing personal assistance, and by ensuring that women with disabilities can retain their legal capacity and freedom.

Violence against women with disabilities is often an act that is perpetrated against what is perceived to be a 'faulty being' and is a demonstration of a socially acceptable form of power and control over a woman's body and mind.

Recommendations

A broad range of actors have important roles to play in ensuring the rights of women with disabilities against violence. These stakeholders include national and local governments, the United Nations (particularly UN Women and the UN Population Fund), service providers, donors and civil society (including women's organisations, human rights groups, HIV organisations, and disabled persons' organisations). The recommendations are:

1. Promote the inclusion of women with disabilities in mainstream efforts to address violence against all women by ensuring that women with disabilities can physically access programs and services, by arranging transportation or support, or by providing sign language interpretation, among other efforts, and by ensuring that such programs do not exclude any woman on the basis of her disability (including psychosocial disability).
2. Recognise the heterogeneity of disability and ensure that women with all types of experiences of disability are included in all measures concerning women with disabilities, and that such measures are of equal value to all women with disabilities.
3. Take measures to fight stigma, discrimination and all forms of violence against women and girls with

disabilities, for example through awareness campaigns and community discussions.

4. Create accessible channels for distributing information, consulting, and reporting about all forms of violence against women and girls with disabilities.
5. Collect data on the number of women with disabilities who access services and programs for preventing violence against women and serving victims of such violence and use this data to develop more inclusive initiatives.
6. Educate women and girls with disabilities about their human rights.
7. Provide women with disabilities with information and counselling on sexual and reproductive health issues and develop advocacy, information, and support services for women with disabilities who are survivors of all forms of violence.
8. Disseminate information in formats that are accessible to people with learning and sensory disabilities, such as through Braille, sign language, and easily understood language.
9. Investigate the causes of all forms of violence against women with disabilities and specifically on the needs of elderly women, single women, indigenous women and women who live in rural areas with regard to the isolation and victimisation that can contribute to violence in such circumstances.
10. Ensure that all research, actions, and advocacy related to violence against women with disabilities incorporates the forms of violence identified by women with psychosocial disabilities, including psychiatric assault, and fully investigates the experiences of these women.
11. Adopt laws and policies recognising that all actions that violate the right to bodily integrity of women with disabilities are illegal, including psychiatric assault and forced institutionalisation, and should be considered acts of violence.
12. Educate parents, partners, nurses, caregivers and other health care service providers to deal respectfully with disability and offer quality care when their help is required. Train communities on how to include and communicate with people with different types of disabilities to avoid isolation of women and girls with disabilities.
13. Actively include diverse women with disabilities in developing and implementing programs, policies
14. and protocols for service providers, law enforcement officers, and other personnel who work with women with disabilities.
15. Train women with disabilities to organise and manage support services efficiently, to develop skills and abilities for economic self-sufficiency, and to use technological aids that that lead to greater independence.

Notes

[1] See World Organisation Against Torture – Violence against Women, available at: www.omct.org/index.php?id=EQL&lang=eng.

[2] 'Report on Violence and Discrimination against disabled people', European Disability Forum, Belgium, 1999.

[3] Marita Iglesias, 'The nature of violence against disabled people', 2004, http://www.nda.ie/cntmgmtnew.nsf/0/BE967D49F3E2CD488025707B004C4016?OpenDocument.

[4] Special Rapporteur on Torture (UN Doc. A/63/175) and by Young et al 1997.

[5] See also Tina Minkowitz. The UN CRPD and the Right to be Free from Nonconsensual Psychiatric Interventions, *Syracuse Journal of International Law and Commerce* 32(2) 2007, and related documents and presentations on forced psychiatric interventions as torture available at http://www.chrusp.org/home/resources.

[6] See Final Report of OHCHR Expert Seminar on Freedom from Torture and Persons with Disabilities, available at www2.ohchr.org/english/issues/disability/documents.htm.

[7] 'Violence and women with disability', M Iglesias, AIES, Spain, 1998; 'Men's Violence against Women with Disabilities', Swedish Research Institute for Disability Policy, Sweden, 2007.

[8] First National Study on Crime against Persons with Disabilities, Department of Justice, Office of Justice Programs, US, 2009.

[9] Young, M, M Nosek, C Howland, G Chanpong, and D Rintala 1997, 'Prevalence of abuse of women with physical disabilities', *Archives of Physical Medicine and Rehabilitation,* 78, Supplement: s34–8.

[10] Young et al, op cit; Nixon, J 2009, 'Domestic violence and women with disabilities: locating the issue on the periphery of social movements', *Disability & Society*, 24(1), 77–89.

[11] Nixon, op cit.

[12] Ibid.

[13] Saxton et al, op cit.

Disability and Development Organisations and Networks

1. Networks

Australian Disability and Development Consortium (ADDC)

www.addc.org.au

The ADDC is a national network focusing attention, expertise and action on disability issues in developing countries, building a national platform for disability advocacy. Its mission is to promote the rights and inclusion of persons with disabilities in development activities, advocating that disability be fully integrated into all Australian development programs and policies.

Disability Rights Promotion International (DRPI)

http://www.yorku.ca/drpi

DRPI is a collaborative project working to establish a monitoring system to address disability discrimination globally. It has adopted a holistic approach to disability rights monitoring, with three focus areas: individual experiences monitoring, systemic monitoring and media monitoring.

Dutch Coalition on Disability and Development (Netherlands)

www.dcdd.nl

DCDD's mission is to improve the condition of persons with disabilities by promoting equality of rights, communal responsibility for care, and social integration.

First Peoples Disability Network (FPDN)

FPDN is a national network for Aboriginal and Torres Strait Islander people with disability.

Global Partnership for Disability and Development, World Bank (GPDD)

www.worldbank.org

GPDD was formed to increase collaboration among development agencies and organisations to reduce the extreme poverty and exclusion of a substantial number of children, women and men with disabilities living in poor countries. The GPDD encourages mainstreaming to achieve MDGs.

International Disability and Development Consortium (IDDC)

www.includeeverybody.org

IDDC, founded in 1994, is a global consortium of currently 20 NGOs supporting disability and development work in more than 100 countries around the world.

Its aim is to promote inclusive development internationally, with a special focus on promoting the full and effective enjoyment of human rights by all disabled people living in economically poor communities in lower and middle-income countries.

International Indigenous Network of People with Disabilities (IINPWD)

http://groups.yahoo.com/group/IINPWD

International Centre for the Advancement of Community Based Rehabilitation

http://cbrresources.org

To facilitate the worldwide exchange of CBR information.

Mind Freedom

http://www.mindfreedom.org/

MindFreedom aims to empower psychiatric consumers and survivors to be heard more effectively by their communities, care providers, and policy makers.

World Federation of the Deaf (WFD)

http://www.wfdeaf.org

WFD was established in Rome, Italy, in 1951. It is an international, non-governmental central organisation of national associations of Deaf people, with a current membership of associations in 130 countries worldwide.

WFD's philosophy is one of equality, human rights and respect for all people, regardless of race, nationality, religion, gender, sexual preference, age and all other differences. WFD supports and promotes in its work the many United Nations conventions on human rights, with a focus on Deaf people who use sign language, and their friends and family.

World Network of Users and Survivors of Psychiatry (WNUSP)

http://www.wnusp.net

WNUSP is an international organisation of users and survivors of psychiatry advocates for human rights of users and survivors speaks internationally for users and survivors promotes the user/survivor movement in every nation around the globe links user/survivor organisations and individuals throughout the world

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2. International NGOs with a disability and development focus

Action on Disability and Development (ADD)

www.add.org.uk

ADD is a UK-based NGO supporting organisations of disabled people in Africa and Asia to influence policy and practice.

Asia–Pacific Development Centre on Disability (APCD)

www.apcdproject.org

The APCD project is a technical cooperation project between the Government of Japan and the Government of Thailand. The project's goal is to promote the empowerment of people with disability and a barrier-free society in developing countries in the Asia and Pacific region.

Australian Business Volunteers (ABV)

http://www.abv.org.au

ABV exist to contribute towards the alleviation of poverty in developing communities and contribute towards their sustainable growth by leveraging the skill and knowledge of business experts. Experts volunteer their time and experience to mentor clients on specific business and organisational needs. By transferring knowledge and skills, clients gain both the necessary assistance and the ability to carry on once the volunteer expert has departed. By helping businesses to grow and become sustainable, ABV assists communities who benefit from a better skilled workforce and increased employment opportunities

Australian Youth Ambassadors for Development (AYAD)

http://www.ayad.com.au

The AYAD Program provides skilled young Australians with the opportunity to volunteer overseas in Asia, the Pacific and Africa.

Bond (British Overseas NGOs) Disability and Development Group

www.bond.org.uk/wgroups/disability/index.html

Supports INGOs' and donors' work more effectively to include people with disability in all development work.

Centre for International Rehabilitation (CIR)

www.cirnetwork.org

CIR is a Chicago-based not-for-profit organisation that develops research, education and advocacy programs to improve the lives of people with disability internationally.

CBM International(CBM)

www.cbm.org.au and www.cbm.org.nz

CBM is an international Christian organisation whose primary purpose is to improve the quality of life of people with disability and reduce the risk of disability, particularly for people living in the poorest areas of the world.

Disability Awareness in Action (DAA)

www.daa.org.uk

DAA is an international human rights network, run *for* and *by* disabled people with a primary focus on developing countries.

Disability: Knowledge and Research (UK)

www.disabilitykar.net/index.html

This website brings together all the findings, research papers and activities from the Disability Knowledge and Research program 2003–2005.

Disabled Peoples' International (DPI)

www.dpi.org

DPI is a network of national organisations or assemblies of persons with disabilities, established in Canada in 1981 to promote human rights of persons with disabilities through full participation, equal opportunity and development and international cooperation**.**

Disability Rights International

http://www.disabilityrightsintl.org

Disability Rights International is dedicated to promoting the human rights and full participation in society of people with disabilities worldwide.

Economic and Social Commission for Asia and the Pacific (ESCAP)

www.unescap.org

ESCAP promotes rights and education for people with disability in developing countries and in the Pacific specialises in developing appropriate rights-based policy and frameworks for the Pacific.

Fred Hollows Foundation

www.hollows.org.au

An international development organisation focusing on blindness prevention and Australian Indigenous health.

GLADNET

http://www.ilr.cornell.edu/edi/gladnet/default.cfm?pageID=1

GLADNET's objective is to promote disability policy and program reform with emphasis on integrated training and employment options for working age persons with disabilities. These objectives are achieved through collaborative applied research projects, and by the global exchange of information via the Internet.

GLADNET has a established a Thematic Working Group to monitor global and regional progress on the implementation of the UNCPRD in relation to Article 27 — Work and employment; Article 28 — Adequate standard of living and social protection; and Article 32 — International cooperation in the areas of training, work and employment.

Handicap International

www.handicap-international.org.uk

INGO working in partnership with local organisations and government institutions to build capacity, raise awareness on disability and landmine issues, and directly implement in emergency situations.

IDEA net

http://www.ideanet.org/content.cfm?id=5B&newCommunity&CFID=1195991&CFTOKEN=85636133

The IDEAnet is a global collaboration of individuals and institutions that provide medical services and humanitarian relief. The mission of IDEAnet is to foster collaborative efforts to use distributed learning and volunteer telemedicine to address health disparities and foster effective, sustainable health services. In order to best achieve this mission, the network is divided into two topically based communities of practice: the Rehabilitation Services Community and a Telemedicine Resource Center. The IDEAnet website, which is sponsored by the Center for International Rehabilitation (CIR) is designed to serve these communities and to facilitate communication and collaboration with the goal of improving practice in each of these areas.

Impact Foundation (UK)

www.impact.org.uk/index.asp

IMPACT is an international program to prevent and alleviate needless disability. There are 17 Impact Foundation organisations globally.

Inclusion International

http://www.inclusion-international.org

Inclusion International is a global federation of family-based organisations advocating for the human rights of people with intellectual disabilities worldwide. For over 40 years Inclusion International has been committed to the promotion of these human rights and our organisation now represents over 200 member federations in 115 countries throughout five regions including the Middle East and North Africa, Europe, Africa and the Indian Ocean, the Americas, and Asia Pacific.

International Agency for Prevention of Blindness (IAPB)

www.iapb.org/objective

IAPB is a coordinating, umbrella organisation to lead an international effort in mobilising resources for blindness prevention activities.

International Council for Education of People with Visual Impairments (ICEVI)

www.icevi.or

ICEVI is a global association of individuals and organisations that promotes equal access to appropriate education for all children and youth with visual impairments. Works in Africa, East Asia, Latin America, Pacific and West Asia

International Centre for Eyecare Education

m.ho@icee.org

Provides eyecare education to prevent avoidable blindness.

International Labor Organisation (ILO)

www.ilo.org/employment/disability

ILO is a UN organisation that has a focus on employment for people with disability, preventing work-related disability and vocational rehabilitation to enable people with disability to secure, retain and advance in suitable employment.

Leonard Cheshire

www.lcdisability.org

Supports over 21,000 disabled people in the UK and works in 52 countries, the organisation campaigns for change and provides innovative services that give people with disability the opportunity to live life their way.

Leprosy Mission

www.leprosymission.org.au

A non-denominational Christian organisation, with over 130 years experience in leprosy work.

Mobility International (USA)

www.miusa.org

Empowering people with disability around the world to achieve their human rights through international exchange and international development.

Motivation Charitable Trust (UK)

www.motivation.org.uk

Motivation is an international disability and development charity working in low-income countries to enhance the quality of life of people with mobility disabilities.

Sense International

www.senseinternational.org.uk

Sense International helps deaf blind people in the developing world to communicate, connect, interact and flourish

Social Development and Social Services

http://www.sdvsnepal.org/deafprogram.php

To raise awareness of issues for people who are deaf, advocate for their rights

Sight Savers International

www.sightsavers.org

Work to combat blindness in developing countries, restoring sight through specialist treatment and eye care. Support people who are irreversibly blind by providing education, counseling and training.

Source International Information Support Centre

www.asksource.info

An international information support centre designed to strengthen the management, use and impact of information on health and disability.

Vida Volunteers

http://www.vidavolunteers.com.au

VIDA (Volunteering for International Development from Australia) is part of the Australian Government's Volunteer Program. The VIDA Program places skilled Australian volunteers in developing countries in the Asia Pacific region in line with Australian Government development priorities and the Millennium Development Goals. VIDA volunteers work with local counterparts to reduce poverty and achieve sustainable development results in the communities in which they work through skills and knowledge exchange, institutional strengthening and capacity building.

Vision 2020

www.v2020.org

Part of a World Health Organisation and International Agency for the Prevention of Blindness initiative. Provides global support for eyecare and prevention of blindness.

World Institute on Disability(WID)

http://wid.org/programs/international

WID's International Program provides training and technical assistance to disabled persons organisations (DPOs) in developing countries to conduct effective disability advocacy, community barrier removal and public education campaigns; develops programs and national policies; and creates networks and national coalitions to promote the full inclusion of people with disabilities into all aspects of society. Since 2004, WID has worked in Armenia, Azerbaijan, Colombia, Georgia, Iraq, Russia and Uzbekistan.

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3. Australian, New Zealand and Pacific & Asian disability organisations with a development focus

Asia-Pacific Development Centre on Disability

www.apcd.org

Based in Bangkok APCD funds a variety of projects in Asia and the Pacific that relate to disability but largely focusing on capacity building and awareness raising.

ASSERT Timor-Leste

dulceassert@gmail.com

The DPO based in Dili representing people with disability in Timor-Leste. ASSERT comprises five NGOs.

AusAID

www.ausaid.gov.au/disability

The Australian Agency for International Development has a Disability Task Force, has developed a disability strategy to guide the aid program and is providing funding for disability support programs in the Pacific.

Australia Pacific Islands Disability Support (APIDS)

www.apids.org

Acts as a broker between organisations and individuals in Australia who wish to support people with disabilities and disabled peoples' organisations in the Pacific; facilitates voluntary work by Australian professionals to assist with the expertise required by relevant organisations in the Pacific Islands; raises funds from Australian and international public, private and government sources; advocates to the Australian Government to raise the priority of funding for disability organisations in the Pacific Islands; responds where possible to other opportunities to support people with disability and related organisations in the Pacific.

Australian Federation of Disability Organisations

www.afdo.org.au

An umbrella organisation for Australian disability organisations.

Australian Volunteers International (AVI)

www.australianvolunteers.com

Provides volunteers with disability expertise who work in partnership with people from developing countries in the Pacific and Asia**.** Has new disability programmes for Fiji and Kiribati.

Bangladesh Prodibandhi Kallyan Somity (BPKS)

www.bpksbd.org

Supports small disabled peoples organisations in Bangladesh to strengthen organisational capacity. Partners with Caritas Australia.

CBM Australia and CBM New Zealand

www.cbm.org.au / www.cbm.org.nz

Christian Blind Mission in Australia and New Zealand have supported DPOs in the Pacific and CBM Australia has been instrumental in getting recognition of the need to incorporate disability into development activities. CBM Australia advocated for and established the Australian Disability and Development Consortium.

Cook Islands National Disability Council

www.cook-islands.gov.ck

Cook Islands NDC is an advocacy body for people with disability and a convening and coordination body for disability stakeholders in the Cook Islands to ensure the interest of PWD are addressed. In 2003 developed a national policy on disability and a national plan of action for implementing it.

Disability Australia

www.dpi.org.au

Disability Australia is the Australian arm of Disabled Peoples' International, which are people with disabilities of the world acting together for their mutual advancement. It is an organisation operating for the benefit of all people with disability.

Disabled Peoples Advocacy Association, Vanuatu (DPA)

jalynch@vanuatu.com.vu

DPA, Vanuatu provides advocacy and awareness raising about disability, human rights and women's rights in Vanuatu. It has raised awareness among politicians and government services and was instrumental in getting the Government of Vanuatu to sign the Convention on the Rights of People with Disability – the first country in the Pacific to do so.

Disabled People's International Asia-Pacific (DPI/AP), Thailand

www.dpiap.org

DPI is an international cross-disability, self-help, human rights organisation of people with disability. It promotes full participation and equal opportunity through providing 'a voice of our own'. DPI holds consultative status with the UN and collaborates with many international agencies.

Fiji National Council for Disabled Persons

www.fncdp.org

FNCDP is the coordinating body for all Fiji organisations dealing with the care and rehabilitation of people with disabilities. It has eight member organisations listed on its web site. FNCDP is responsible for policy development, awareness raising, seeking funding, community rehabilitation services and training.

Fred Hollows Australia

www.hollows.org.au

An Australian-based international development organisation focusing on blindness prevention.

Motivation Australia

www.motivation.org.au

Works in partnership with local organisations in Asia, the Pacific and remote rural Australian communities to enhance the quality of life of people with mobility difficulties.

National Assembly of Disabled People — Papua New Guinea

nops@online.net.pg

Provides advocacy and information on disability in PNG.

National Council of People with Disabilities in Samoa

disabilitycouncil@samoa.ws

Samoa's major disability organisation.

NZAID

www.NZAID.govt.nz

The New Zealand development assistance organisation that has supported the establishment and capacity building of DPOs in the Pacific. Their document 'Free and equal: a review of NZAID Pacific Regional Disability Programmes' (2004) provides useful information and advice**.**

Pacific Disability Forum (PDF)

www.pacificdisability.org

Based in Fiji, PDF was first started in 2002 and was incorporated in 2004. It is the peak Pacific disability NGO representing Pacific countries and territories. It works towards inclusive, barrier free, socially just and gender equitable societies that recognise human rights, the potential of people with disabilities. PDF is responsible for Pacific-wide high level advocacy, for running workshops, conferences and developing disability and development policy.

Pacific Island Forum Secretariat

frederickm@forumsec.org.fj

The Pacific Island Forum Secretariat Social Policy Division has a strong disability focus. It provides country by country disability profiles and information on Pacific disability policies, strategies and plans of action.

People with Disability Australia (PWDA)

www.pwd.org.au

PWDA is an organisation of and for people with disability and part of the organisations that comprise Disabled People's International (DPI). PWDA is a cross-disability organisation that provides individual and systemic advocacy as well as information on disability at state, country and international levels. Has a strong focus on disability rights**.** It has a strong focus on capacity building partnerships with DPOs in the Asia Pacific Region.

Scope

www.scopevic.org.au

A not for profit organisation providing disability services to children and adults with physical and multiple disabilities. Scope is committed to overcoming personal, structural and attitudinal barriers that prevent people with disability from participating in community life.

Solomon Islands Disabled Peoples' Association

Savina_nongebatu@yahoo.com.au

The association provides community support for people with disabilities.

Sport and Development Organisation

http://www.sportanddev.org/en/learnmore/sport_and_disability2/

Sport & Development' refers to the use of sport as a tool for development and peace. This organisation promotes inclusion of people with disability in sport.

Survivor Corps

www.survivorcorps.org/NetCommunity

Te Toa Matoa Kiribati Disabled Peoples Drama Group (TTM)

TTM uses drama and entertainment as a means of providing awareness of the abilities of people with disabilities. It develops and performs community drama as well as performing for radio and TV.

Vision 2020 (Australia)

www.vision2020australia.org.au

Part of a WHO and the International Agency for the Prevention of Blindness initiative. Vision 2020 links 57 Australian organisations involved in local and global eye care service delivery, health promotion and development, low vision support, vision health rehabilitation, eye research, professional assistance and community support, leading advocacy efforts and raising community awareness about good eye health and vision care.

Vision Pacific Trust, New Zealand

tewai@visionpacific.org.nz

Women with Disabilities Australia Inc (WWDA)

www.wwda.org.au

WWDA seeks to ensure the advancement of education of society to the status and needs of women with disabilities in order to promote equity, reduce suffering, poverty, discrimination and exploitation of women with disabilities. WWDA is unique, in that it operates as a national disability organisation; a national women's organisation; and a national human rights organisation.

Women with Disability Pasifika Network

Sainimili_t@yahoo.com

A Pacific regional network of women with disabilities. Focuses on advocacy and awareness raising.

4. Disabled Persons Organisations (DPO)

Organisation	Country	Contact	Email/Web address
Bangladesh Protibandhi Kallyan Somity (BPKS)	Bangladesh		http://www.bpksbd.org
Cambodian Disabled Peoples Organisation	Cambodia	Saorath Ngin	director@cdpo.org
Cook Island Women With Disabilities	Cook Islands	Marjorie Boaza	Cido@intaff.gov.ck
Pacific Disability Forum (Peak body)	Fiji		ceo@pacificdisability.org program@pacificdisability.org
Fiji Disabled Peoples Association	Fiji	Elenoa Kaisau	fdpa@connect.com.fj www.fdpa.org.fj
Te Toa Matoa	Kiribati	Teewata Rokete	T01rocky@hotmail.com
Nuanua O Le Alofa Inc. (NOLA)	Samoa	Nofovaleane Mapusua	disabilitycouncil@samoa.ws
Disabled Peoples Association of Solomon Islands	Solomon Islands	Joel Virala or Savina Nongebatu Daulaasi	savinafnongebatu@gmail.com
Disabled Peoples International (Asia Pacific Region)	Thailand	Saowalak Thongkuay	saowalak@dpiap.org http://www.dpiap.org/
Ra'es Hadomi Timor Oan	Timor Leste	Joaozita dos Santos	Joaozito.dpo@tlmtl.org
Naunau 'Oe 'Alamaite Tonga Disability Assoc.	Tonga	Lotolua Talafaiva	Nata_tonga@yahoo.com www.natatonga.ning.com
Disabled Peoples Advocacy Association	Vanuatu	Nelly Caleb	dpasanto@vcanuatu.com.vu www.dpaav.org
National Assembly of Disabled People	Papua New Guinea		nops@online.net.pg

Note:

Relating to 'The Convention on the Rights of Persons with disabilities: Why it is needed' – page 20.

AusAID's Disability Inclusive Development Reference Group

Terms of Reference

Context

1. The *Development for All* strategy was launched by the Australian Government on 25th November 2008. The strategy guides the aid program towards considering and meeting the needs and priorities of people with disability. The purpose of the *Development for All* strategy is to ensure that people with disability are included in planning, implementation, monitoring and evaluation processes in a genuine manner, and that they share equally in the benefits of Australia's development assistance.
2. Strengthening the focus on disability in Australia's international development assistance is integral to sustainable development and an essential part of achieving the Millennium Development Goals (MDGs). The focus also supports Australia in meeting its obligations under the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), particularly Article 32 which requires States Parties to ensure that international cooperation is inclusive of and accessible to people with disabilities.
3. To ensure that the transparent consultative approach taken during the development of the strategy is formalised, the *AusAID Disability-Inclusive Development Reference Group* (Reference Group) has been established to guide the implementation and be part of the accountability mechanisms for the strategy.

Purpose

4. The *AusAID Disability-Inclusive Development Reference Group* (the Reference Group) is a small group which provides high level guidance on disability-inclusive development and helps to shape AusAID's implementation of the *Development for All* strategy. The Reference group will provide advice to AusAID on its progress against the strategy. Its role is to help guide Australia's aid program to ensure that the activities implemented are consistent with and fulfil Australia's obligations under international law (the CRPD), policies and international development frameworks including the Paris Declaration and the Accra Action Plan on development effectiveness.
5. The Reference Group is an honorary advisory group. Its role is to inform and provide advice on AusAID's policy and program activities. However, it does not have a role in the final decisions made on policy and programming, funding or other contractual arrangements related to implementation of the strategy. These decisions will be made by AusAID based on Government policies and Commonwealth procurement processes.

Membership

6. The Reference Group is a small group of up to six members. The Reference Group comprises of International and Australian leaders and active participants in disability-inclusive development, including people with disability.
7. Membership is by invitation from AusAID. Final decision about any changes to the membership and composition of the Reference Group membership is the responsibility of AusAID. The current Reference Group members will provide advice and can make recommendations on the membership and composition of the group.
8. Selection of members is on the basis of the individual's standing in the disability community, their knowledge and practical experience in disability-inclusive development particularly in the Pacific and Asia regions and in areas that are of highest priority and most relevant for AusAID in implementing the strategy.

Key Functions

9. The key functions of the Disability-Inclusive Reference Group are to:
    i. Directly engage with AusAID's senior management (senior management, priority implementing areas in Canberra and country programs) to provide advice and guidance in support of implementation of the *Development for All* strategy, ensuring it is consistent in particular with the CRPD and other international development policies and frameworks.
    ii. Engage with, provide advice and guidance to the AusAID Disability-Inclusive Development team (DID) through Assistant Director General and Director responsible for guiding AusAID's efforts in disability inclusive development.
    iii. Provide inputs and advice on performance management, monitoring and review of the implementation of AusAID's *Development for All* strategy.
    iv. In members' capacity as representatives of and leaders in the disability and development community, facilitate and support AusAID's engagement and consultation with people with disability.
    v. Provide a mechanism for communication, exchange of ideas and lessons learnt on good practice and emerging issues in disability-inclusive development between AusAID and external stakeholder groups.

Key Activities

10. The Reference Group will carry out the following key activities:

i. Participate in twice yearly meetings with relevant Government representatives, senior AusAID staff, members of the Disability-Inclusive Development Team and others as appropriate that will contribute to the planning and monitoring of the implementtation of the *Development for All* strategy.

ii. Undertake concurrent appraisal and feedback to AusAID on implementation of disability-inclusive development in the aid program.

iii. Engage with the Parliamentary Secretary for International Development Assistance and AusAID's Senior Executive to provide opinion and advice on the implementation of the *Development for All* strategy and other relevant issues on disability-inclusive development.

iv. As appropriate engage with other key stakeholders such as the Australian Disability Discrimination Commissioner and the Australian representative on the UN Committee for the UN CRPD.

v. Inform on and participate in the mid term review of the *Development for All* strategy by providing inputs on the design of the review process and analysis of the findings.

vi. Provide additional selective inputs on the invitation from AusAID's Director of the Disability-Inclusive Development Team.

Operations

11. Assistant Director General (OPS) and Director Disability-Inclusive Development AusAID are the key points of contact regarding the Reference Group's engagement with AusAID. Coordination of Reference Group meetings, communication and records are the responsibility of the Director Disability-Inclusive Development. The Reference Group, in consultation with Assistant Director General (OPS) and Director Disability Inclusive development, will develop an annual work agenda, which will identify key issues that the Reference Group will focus on, monitor and report against for the 12 month period.

12. It is expected that for at least one meeting per year, there will be participation of the Parliamentary Secretary and/or the Director General of AusAID. It is anticipated that when appropriate meetings might be held outside Australia and likely in a location where AusAID is implementing disability-inclusive programs. This will enable the Reference Group to engage with stakeholders and partners involved in these activities.

13. AusAID will cover all members' expenses associated with travel, including per diems, accommodation, airfares and relevant accessibility and assistance requirements.

Governance

14. The following will govern the operations of the Reference Group;

    i. The initial tenure of members is for three years (2009–2012). A mid term review of the strategy *Development for All* will take place in early 2012. The ongoing existence, role and makeup of the Reference Group will be determined as part of the outcomes of the mid term review.

    iii. Members might change their individual professional role during their period of tenure. Where this occurs, AusAID with the individual member will decide the appropriateness and relevance of continuing as a member of the Reference Group.

    iv. The list of members will be kept updated and publicly available by AusAID.

    v. Members and AusAID will at times have access to certain information that may lead to the risk of potential conflict of interests. Where this is identified by AusAID and/or the member(s), it will be managed on a case by case basis, ensuring that any potential breach of confidentiality, advantage or other gains by AusAID, members and/or their respective organisations is avoided.

    vi. Meetings and other reports approved by the Reference Group will be made publicly available by AusAID through communiqués.

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www.addc.org

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