



Development Bulletin

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Disability, Disadvantage and Development in the Pacific and Asia

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Australian Disability+Development Consortium



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Development for all

Bob McMullan MP,

Parliamentary Secretary for International Development Assistance

One of my proudest achievements in a long career as a Member of Parliament has been the launch of *Development for All* — Australia's first strategy to specifically address the needs and priorities of people with disability living in developing countries in the Asia Pacific region.

I have long held the belief that people in poor countries are doubly disadvantaged by poverty and social and economic exclusion. They are too often excluded from development processes and programmes. Yet they have as much right to take part in everyday life, to be part of decision making and to have the same social and economic wellbeing as everyone else.

This is not a small problem. The UN estimates about 10 per cent of the world's population — about 650 million people — have a disability and about one-quarter of the world's households are impacted in some way by disability. Most of these are in developing countries, and most of them are in our region. Disturbingly, levels of disability and impairment are expected to further increase as a result of population growth, lifestyle diseases, conflict and other causes.

I congratulate the Australian Disability and Development Consortium and the ANU for addressing these issues in this publication. It is very timely given the Australian aid programme is moving into an exciting new phase with the start of planning and early implementation of the *Development for All* strategy.

Already there is evidence of increased recognition of disability as a core development issue and many of our development partners are looking to us to see how we incorporate disability-inclusive development into the aid programme.

Over the past year we have achieved a number of milestones in advancing the cause of people with disability. We have launched *Development for All*, we have ratified the UN Convention on the Rights of Persons with Disabilities (CRPD), and Australia is developing a national strategy for people with disability.

When we held consultations on our disability strategy we received over 500 written submissions from people with disability, their families, carers and the organisations they represent. It was as though we had opened the floodgates.

Strong leadership will be crucial to keep up this momentum and the profile for disability-inclusive development that we have built through the strategy consultation process. This leadership will be demonstrated in a number of areas — in using international events and forums to advocate for increased attention and resources for people with disability, in building the capacity of people with disability themselves to take the lead in promoting their rights, and in integrating the needs and priorities of people with disability into everything we do. Disability will not be treated as a stand-alone activity.

However, there are strategic gaps where Australia can demonstrate leadership on disability issues, none more important than investing in better knowledge, and in building a robust evidence base for our work.

Already we are supporting some key multilateral work in knowledge and research, including the World Report on Disability and Rehabilitation, a joint initiative of WHO and the World Bank, due for publication later this year. We are also talking

with international agencies such as the UK Department for International Development (DFID) on cross-cutting research, and working with a number of development partners to support research to advance the implementation and monitoring of the CRPD. Our own Australian Development Research Awards have already identified disability as a priority research theme and will be supporting valuable work in this area.

There is much to do and many gaps in knowledge. The challenges of data collection and consistency in definitions are large. Investment in research will not only strengthen our knowledge base about disability, but will make our development activities more effective, more relevant and more dynamic.

Consultations raised many important issues that need to be addressed if people with disability are to be fully included in social and economic life. However, not every suggestion or recommendation proposed by stakeholders could be accommodated in our disability strategy. That would have been neither possible nor sensible. Instead, we are aiming to lay the foundation for sustainable change in the way the aid programme works, and build capacity to deliver the strategy's three main outcomes: to improve the quality of life for people with disability, to reduce preventable impairments, and to foster effective leadership on disability and development.

By improving the quality of life for people with disability we will bring people who are the subjects of stigma or neglect out of the shadows and into the mainstream of everyday life. We will concentrate our efforts on two areas — education and infrastructure.

There are good reasons for this. Education opens doors to both social inclusion and economic success. It is the platform for all other development objectives. The UN estimates that less than 10 per cent of young people with disability have access to primary education. The figure is even lower for girls with disability or girl carers. These girls are not trained for economic self-sufficiency and as adults often do not marry, rarely inherit or own property and are excluded from social and community activities.

Access to infrastructure is also fundamental to social and economic development. If people can't get into schools or workplaces or are unable to use roads and transport, they cannot be productive or participate fully in their communities.

Where we have a role in the planning or construction of new roads, buildings or facilities in partner countries, we will ensure they suit people with disability. We will build on existing efforts in infrastructure to improve access to essential infrastructure and services.

We are already using our expertise and experience to help reduce preventable impairments in Asia and the Pacific,

especially avoidable blindness and road traffic accidents. People in lower socio-economic groups in developing countries are at greater risk of the range of factors that cause impairment such as poor maternal health and diet, poor access to water and sanitation, and immunisation. In many emerging economies, health and safety in the workplace and increased traffic on poorly built roads are contributing to increasing levels of impairment. Our assistance will increase opportunities for people with low vision and blindness to have the same rights and freedoms as others and to benefit from improved road safety.

In fostering leadership we will put people with disability at the centre of our development assistance efforts, including in key decision-making processes such as design, monitoring and review. The only way we can meaningfully understand the issues that impact on the lives of people with disability is if we work with them, their families and carers, as well as their broader communities and local communities. People with disability know best what they need and have the potential to be powerful advocates. We must support their efforts to find practical solutions to the barriers they face to social and economic participation.

Australia applauds the work already being done by many countries in Asia and the Pacific to promote disability inclusion. Some have signed international agreements such as the Bikawo Millennium Framework for Action and the CRPD. Individuals and organisations representing people with disability are becoming more active in decision making. However, despite these advances, the lack of resources, assistive devices, technical knowledge and capacity hinders further progress. In particular, people with disability in rural and remote areas struggle to access social services, and those with multiple disabilities frequently remain marginalised.

The Australian Government is seriously committed to the Millennium Development Goals. We intend to continue increasing our aid budget to 0.5 per cent of Gross National Income by 2015 to help countries meet MDG targets. Yet we cannot achieve the MDGs if we do not improve the circumstances of people with disability. This group should not be bearing the dual burden of poverty and social and economic exclusion. In the 21st century, we can do better than this. I am proud that Australia's aid programme has taken firm steps to help overcome barriers that make life unnecessarily difficult for people with disability.

This issue of the *Development Bulletin* will make an invaluable contribution to improving our understanding of disability and development. By making a difference to the quality of our efforts, it will help all of us to make a difference to the lives of people with disability.

Introduction: Disability, disadvantage and development

Pamela Thomas, Development Studies Network, The Australian National University

Background

The idea for this issue of *Development Bulletin* was first raised early in 2007 when Paul Deany, the coordinator of the newly formed Australian Disability and Development Consortium (ADDC), visited the Development Studies Network at The Australian National University to discuss the possibility of an issue of the journal devoted to the relationship between disability and development. Like many academics working in social and economic development this was a relationship I had not considered, although I was aware of the situation of some Pacific Island people with disability. An exhaustive literature search revealed very little but over the following year a clear picture began to emerge — one of poverty, invisibility, exclusion and lack of access to basic human rights — but also one of a few effective small-scale partnerships and support for Pacific disability organisations.

To help create greater awareness of the impact of disability on development and to encourage the inclusion of disability within the development agenda, we planned an international conference with the option of using some of the papers as the basis for a special issue of our journal *Development Bulletin*.

The international conference 'Disability, disadvantage and development in the Pacific and Asia' organised by the Development Studies Network in collaboration with the ADDC, was held in Canberra September 29–30 followed by a Policy Roundtable October 1. The conference, roundtable and this issue of *Development Bulletin* have been supported by AusAID, indicative of their awareness of the need for including disability within their policy, planning and programming. For me, the conference and this journal have involved an almost perpendicular learning curve. It is an on-going journey I am pleased to be making.

Introduction

Contributors to this journal agree that in the Asia Pacific region there are an estimated 400 million people with disability. The actual numbers are uncertain, however, because, like many other aspects of disability in developing countries, there has been very limited national or international academic, government, non government or United Nations scrutiny. Like many people with disability, the critical relationship between disability and development has remained hidden. Disability has not been considered in academic development discourse or theory, and is very seldom apparent in the development literature. Its inter-relationship with disadvantage and poverty is seldom considered in mainstream development policy or planning. It is missing from the Millennium Development Goals, yet it impacts on the possible achievement of all social and economic goals. It has also been missing from international law.

The papers and case studies in this journal begin to address this lack of information and understanding of the relationship between disability and development, and in particular the inter-relationship between disability and poverty. They also highlight recent, dramatic changes in development assistance policy in the Pacific and Asia and provide first-hand experience of community, national, regional and international initiatives that are now beginning to address the invisibility and lack of rights of those with disability.

While some papers provide first-hand experience of discrimination, disempowerment, exclusion, vulnerability and the vicious circle between poverty and disability, the overall focus of the journal is on ability rather than disability. It considers the positive actions of individuals, their families, communities, organisations and governments to address the rights of people with disability and their equal access to development. This includes the role of international conventions and strategies and the development of the Australian Government's disability strategy *Development for All: Towards a disability-inclusive Australian aid program, 2009-2014*.

The common threads that run through the papers are the importance of inclusion and equal opportunities for those with disability; the role of networking and sharing information and skills; the importance of equal human rights for people with disability and the role of the Convention on the Rights of Persons with Disabilities (CRPD) in achieving this; the need to include people with disability in initial planning of any disability-related activities; the need to give special attention to women with disability; and the importance of communicating and utilising the CRPD. Modern communication technologies are seen as valuable tools for creating awareness and implementing the Convention through enabling the formation of powerful alliances of disabled people's organisations (DPOs) which can learn from each other, advocate en bloc, lobby politicians and allow widespread, inexpensive circulation of information.

There remains an urgent need for quality research into many aspects of disability and its links to social and economic development.

The situation

The incidence of disability within populations varies considerably between countries; between urban and rural areas; and between the poor and those better off. Globally around 10 per cent of the population, or an estimated 650 million people worldwide, have one or more disabilities. Around 80 per cent of those experiencing disability live in developing countries and are over-represented among the very poor, but are seldom counted in surveys. Debra Perry makes the point that because of lack of reporting in poorer countries and in poor, isolated areas in particular, current estimates of disability in these situations are likely to be too low.

The discussion on the inter-relationship between poverty and disability shows clearly that poverty is both a cause and consequence of disability. Poverty may cause disability through malnutrition, poor health care, dangerous living conditions, lack of communication and information, while disability results in high rates of illiteracy, lack of access to health care, unemployment, lack of representation, and often lack of mobility, creating a vicious circle.

It is estimated that 98 per cent of children with disability in developing countries do not attend school so are ill equipped for employment. This reinforces the poverty-disability cycle. The failure of development and international aid programmes to include a disability perspective fundamentally entrenches the exclusion of people with disability from development efforts, continuing the cycle of poverty and disability. In all countries, women with disability are usually the poorest members of society. They suffer multiple discrimination and frequently, abuse and sexual harassment.

In the Pacific, people with disability have until very recently been ignored and excluded from national development planning and priorities. Setareki Macanawai and Alastair Wilkinson suggests that urbanisation and changing social arrangements in most Pacific countries together with increasingly high rates of diabetes, hypertension and road accidents will lead to an increased percentage of people with disability without a support network.

Using conventions, strategies and policies

While there are a number of international human rights conventions and plans of action which should ensure that the human rights of all people, including the 650 million with disability, are respected, this has seldom been the case. The CRPD addresses the specific situation of people with disability. It is the most detailed statement of human rights by the United Nations to date. The CRPD was adopted by the UN in December 2006 and entered force in May 2008. Unlike other UN Conventions, the CRPD is seen as an 'implementation Convention' setting out a detailed code for how existing rights should be put into practice. It is both a development and a human rights instrument and marks the first time that international cooperation has appeared as a stand-alone article in an international treaty.

In the Pacific, only Australia, New Zealand and Vanuatu have ratified the Convention. 'Ratification of human rights treaties', Graeme Innes suggests, 'is not a priority amongst Pacific Island countries as they consider human rights to be incorporated in their Constitutions'. And, many Pacific Island citizens are unaware that their country has a Constitution let alone its content. Limited understanding about the Convention and human rights means many people with disability lack the tools to lobby their leaders for the policies that affect them. In the Pacific, individual human rights perspectives are often considered incompatible with communal Pacific Island social structures and values.

Access to information is clearly elaborated in the CRPD (Article 9). Robyn Hunt puts forward a strong argument that access to information is fundamental to development and

to human rights, including people with disability. This requires information being provided in formats that are disability friendly.

In developing disability policy, Alastair Wilkinson says that if policy is to have an impact and change attitudes, then the policy development process must be taken to the village and developed within this cultural context. The importance of understanding and supporting people with disability within their cultural context, the value of community-based interventions and the importance of planning interventions and support with people with disability and their communities are reiterated by many contributors.

The development of the strategy *Development for All: Towards a disability-inclusive Australian aid program 2009-2014* provides a good example of widespread community consultation and consideration of different cultural contexts. Kristen Pratt outlines the goals of the strategy as 'all AusAID staff to have the understanding, commitment, skills and resources to ensure that people with disability are automatically and effectively included in development processes and benefit equally from AusAID's aid programme'. This approach is also stressed by Megan McCoy of NZAID. Outlining New Zealand's disability policy framework, McCoy says that as a core human rights issue, disability is considered across a range of their policy and strategic documents that require development of a mainstreaming approach. However, the NZAID health policy supports a twin-track approach which aims to address fundamental inequalities as well as supporting specific initiatives to enhance the empowerment of people with disability. One NZAID programme is giving increased attention to education for children with disability.

Both aid organisations have a clear focus on inclusion and are committed to ensuring their own organisations practice 'disability awareness and inclusion' — a situation that some contributors suggest is not always the case within government or non government disability organisations. Alexander Gartrell suggests that many organisations need internal and external disability mainstreaming.

The economics of disability

The large majority of people with disability face significant barriers to accessing work and the experiences and skills that make work more likely. The workforce participation and incomes of people with disability are significantly lower than others, particularly in the case of women. Education and vocational training are crucial to participation in the labour force but, as Debra Perry suggests, one in three of the world's 77 million children who do not attend school have one or more disabilities. People with disability have great difficulty accessing credit — especially those who face transport barriers. Perry shows that from a global economic perspective, the cost

of disability is between US\$1.37 and US\$1.94 trillion or an average annual global GDP loss per person with disability of between US\$2,486 and US\$8,226. In OECD countries the cost of disability benefits alone is 1.23 per cent of overall GDP. 'People with disability who are not working', she says, 'represent an under-utilised human resource ... when included they contribute to the economic development of their countries'. Jennifer Gersbeck provides an example of the economic cost of impaired or loss of vision that could be prevented and suggests that it is the economic cost of disability that provides a compelling case for decision makers to take action.

Achieving social and economic inclusion

Inclusion of people with disability in education, the workforce, decision making, health and legal services, and access to transport and information are the goals of a number of small and larger initiatives in Asia and the Pacific. In Timor-Leste, an April 2008 survey showed that only one in 10 children with disability attended primary school, the ratio for girls was even lower, although the Constitution affords children special protection against all types of discrimination. Natalie Grove, Justininho Amaral and Jose Freitas point to difficulties faced by the Ministry of Education — 90 per cent of schools were damaged or destroyed in the post referendum violence in 1999 and the education system has few teachers, overcrowded classrooms and high rates of repetition. But, as the authors state, there are some positive indicators. Some children with disability are attending local primary schools and there is a special school in Dili. The Ministry of Education is aware of the situation and a national inclusive education framework will be developed.

Robert Choy raises the issue of the plight of people with disability in humanitarian disasters. He gives the examples of Bangladeshi floods and the Indian Ocean tsunami where the limited mobility of people with disability and their inability to access food and water distributions resulted in a much higher death toll among this population. 'People with disability are doubly vulnerable when emergencies occur on account of their disability and poverty'. He suggests that to address the issue, a community-based disaster planning approach should engage people with disability themselves in its development. The identification and registration of people with disability, including their special needs, should include the 'invisible' people.

In the reconstruction phase, both Choy and Samantha Whybrow recommend that the special requirements of people with disability be incorporated into the design and building of roads, paths, houses, shops, and toilets to ensure they are accessible. But 'unfortunately planners often recreate the inequitable status quo by failing to adapt the design of the rebuilt environment to meet the needs of people with disability'. Universal accessibility for all should be paramount.

Whybrow provides the example of the project 'Access for All' which advocated universal design principles in the reconstruction efforts in Sri Lanka. The project advocated for adaptable housing that would suit the requirements of people with different abilities and mobility levels but it was difficult to get builders to incorporate changes in design.

Emma Pearson and Katy Cologon outline some myths regarding the experiences and beliefs of those people with disability who come from diverse cultural and linguistic backgrounds. In Australia it is believed that people from diverse cultural background 'prefer to look after their own' and are less likely to access services. It is also thought that cultural background is not an issue for people receiving support. However, people with disability are as likely to face discrimination from within their cultural group as from wider social groups. The authors strongly contest the notion that cultural values and practices do not impact on the experience of disability. They call for inclusive and culturally-sensitive disability support services. A call strongly supported by Damian Griffis in his discussion of the situation of Indigenous Australians with disability.

Women and disability

Sainimili Tawake and Andonia Piau-Lynch provide examples of the ways in which the situation of poor women in the Pacific is compounded by disability. Case studies show they are among the poorest of the poor, are often subject to abuse and sexual harassment, are denied access to education and in some cases to marriage. Although in the past, family members often cared for women with disability, these safety nets are eroding with the rise of urban migration, squatter settlements, and unemployment among young people. The first to suffer are women.

Martha Morrow and MC Arunkumar show that the difficulties faced by women with disability may increase HIV vulnerability. As yet, there is little international research on HIV prevalence, risk and vulnerability among people with disability. Stigma, isolation and gender not only enhance HIV vulnerability for people with disability but are barriers to accessing HIV services. Unless services are accessible and comprehensible to those with different disabilities they will not meet the needs of people with disability.

In Australia, Sue Salthouse and Carolyn Frohmader report that available research into levels of violence experienced by women with disability is limited but suggests that the incidence is anything from two to 10 times that experienced by non-disabled women. 'One in five Australian women has a disability but Government policy irrespective of political persuasion has largely ignored this group. As a result, their development needs are parallel to women with disability in the region's developing countries'.

Communication and community-based approaches

More recent approaches to empowering individuals and DPOs involve working within the community and training members of the community to become active in appropriate care for those with disability. This is seen as particularly important in the case of children. Often the problem is one of information, understanding, and of being aware that something can be done and there are services available. Within communities there is little recognition that those with disability also have abilities. The provision of appropriate wheelchairs, making small changes to the access to the house, school or latrine can be undertaken by the community if they are given training and support. Examples of community-based occupational therapy in India, the UK and Solomon Islands point to the need for adapting community-based training to the specific cultural context and social values and beliefs.

Many contributors stress the need for greater recognition of the importance of communication in improving the situation of people with disability. Lack of communication and information, especially to those in rural areas and those who are illiterate, and in particular women, is a major barrier to people with disability being able to seek services or access their human rights. Greater consideration needs to be given to finding appropriate ways to provide information to people with disability and ways to train communities in disability support. Genevieve Wiley provides an example of the value of drama, role play, songs and stories in training community-based rehabilitation workers in Solomon Islands — techniques she believes are valuable when working in communities.

The medical model of disability

In several papers there is discussion on the shortcomings of the medical approach to disability. A more inclusive social approach is required that takes into consideration the social, economic and cultural context of the person with disability and the recognition that disability can be socially constructed and needs a social solution.

In discussing Indigenous Australian communities, Damian Griffis shows that Indigenous people with disability can face multiple barriers to meaningful participation in their own communities — they face double disadvantage of discrimination based both on their Indigenous identity as well as their disability. The prevalence of disability among Indigenous Australian is around twice that of the non-Indigenous population for a range of social reasons — poor nutrition, lack of health care, exposure to violence, and psychological trauma. In their communities, the medical cause of disability can be attended to but there are often social aspects that must be taken into consideration. Historically, the focus on Indigenous Australians with disability

has been from a medical perspective. While this is essential it has come at the cost of failing to recognise the social aspects of disability. The barriers that produce discrimination remain firmly entrenched and interventions often simply treat the health condition without considering the broader implications. For example, ear infections are common among children. They are successfully treated but there are no programmes addressing the acquired learning disability caused by the infection not being treated early enough. People with amputations from diabetes may have a successful operation but nobody provides a wheelchair or crutches so they can retain mobility.

Paul Petrus outlines the way disability is traditionally diagnosed in the Highlands of Papua New Guinea where prescriptions are given according to perceived causes — these are based on signs and symptoms involving the relationship of the patient with the religio-cosmic environment, and can relate to disobeying taboos, sorcery and spirits. With traditionally perceived causes, a medical report does not satisfy the patient, the family or villagers. He concludes that if people are to seek modern disability services, health workers and community-based rehabilitation volunteers need to take the lead in promoting disability awareness and support.

Networking, partnering and volunteering

A number of the case studies illustrate the importance of networking between regional, national and community-based organisations. There are many examples of the importance of exchange of information and of partnerships between developed and developing country DPOs. Volunteers have also played a role in helping strengthen links between organisations. Many Pacific

Island and Asian DPOs are now able to collectively advocate and lobby for inclusion of those with disability. Margaret Gadd illustrates the importance of building partnerships between governments and how one initial contact between a South Australian and a Thai Government department can develop into a valuable and successful partnership.

The ADDC also provides a valuable example of how networking and organisations working together can provide effective advocacy and can bring about concrete and practical changes for improved support for people with disability.

Looking to the future

The papers and case studies indicate that there has already been positive change in disability advocacy, knowledge and services in the region. People with disability are saying ‘no’ to old advocacy paradigms, ‘no’ to charity models of condescending help, ‘no’ to medical models, and ‘no’ to colonial perceptions of how assistance is delivered. People with disability wish to be involved in all levels of society, to be consulted and given employment in the delivery of programmes and services. They also wish to be fully involved in development policy and programmes.

Another positive change has been the inclusion of disability within the Australian aid programme and the development of the disability strategy *Development for All: Towards a disability inclusive Australian aid policy 2009-2014*. The way in which the strategy was developed marks a new consultative and community-based approach for the Australian aid programme.

Perhaps the clearest message from this special issue of *Development Bulletin* has been the importance of inclusion: ‘Nothing about us without us’.

Disability, disadvantage and development in the Pacific and Asia

*Graeme Innes, Human Rights and Disability Discrimination Commissioner,
Australian Human Rights Commission*

There are around 400 million people with disability in the Asia and Pacific region. Over 40 per cent of us are living in poverty. Many of us are prevented from accessing entitlements that are available to other members of our society such as health, food, education and employment.

This paper looks at the value of, and the use of, the Convention on the Rights of Persons with Disabilities (CRPD) as a tool for progress to address this unacceptable situation, with a focus on the Pacific.

There are numerous international human rights conventions, plans of action and declarations which should ensure that the rights of everyone — including the 400 million people with disability — are respected, protected and promoted. In theory, a CRPD should not be necessary. Yet, it is an unfortunate fact that people with disability are amongst the ‘poorest of the poor.’

Ratification of human rights treaties is the first step towards a government recognising the rights of their citizens. It creates a framework for identifying rights-holders and duty-bearers.

Ratification of international human rights treaties in the Pacific region is the lowest in the world.¹ I am cautious here not to be artificial and arbitrary when I speak of the Pacific Island countries as a group. Each country, and indeed, each island and even each village, is unique. They each have different ethnicities, languages and political structures. However, they do share some similarities — in their history of Western colonisation, democracy and Christianity, their small populations, vulnerability to natural disasters and their reliance on subsistence economies.

Ratification of human rights treaties does not seem to be a priority amongst Pacific Island countries. It is important to understand why there is a reluctance to ratify human rights treaties. It is also important to understand what pressures are placed upon the governments of Pacific Island nations. I’ll address just some of these reasons.

Most Pacific Island countries’ constitutions contain bills of rights, something which I note, Australia lacks. However, these bills of rights tend to refer only to civil and political rights and not to economic, social and cultural rights. The reason for this can be traced back to the constitution and political history of the Pacific Island nations. At independence, the majority of constitutional frameworks resulted from the constitutional ideas dictated by Western colonial leaders. Constitutions were drafted without any significant local participation. At that time,

the prevalent human rights thinking within the realm of British constitutionalism were civil and political rights. Accordingly, constitutions of the Pacific Islands followed suit.

This can lead to two conflicting arguments. First, that human rights are enshrined in the constitution and therefore should be adopted on the international level. Alternatively, that international human rights treaties are not needed as they are already enshrined in the constitution.

However, many Pacific Island citizens are unaware of the existence of their constitution let alone its contents. The rights of people with disability are also not included in their constitutions. Joining the international human rights treaty system affords an additional layer of protection for citizens. Civil society groups also use the treaty framework in their promotion of human rights.

The Convention of the Rights of Persons with Disabilities

The CRPD seeks to address the specific needs of people with disability in a similar fashion to other thematic human rights conventions such as the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) and the Convention on the Rights of the Child (CRC). CEDAW and the CRC are the two most ratified human rights treaties in the Pacific. The ratification of these two Conventions has assisted in improving people’s understanding and awareness of women’s and children’s rights through the review of domestic legislation, development of policies and court jurisprudence. Likewise, the ratification of the CRPD will raise awareness about the human rights of people with disability.

An often cited reason for not ratifying human rights treaties, especially those containing economic and social rights, is the increased resource burden that the international human rights treaty framework imposes. This resource burden is felt in terms of both human and financial resources, and at different stages of the treaty process:

- First of all, at the decision stage: it takes resources to review domestic legislation and decide whether the conventions are culturally offensive or acceptable.
- Secondly, at the ratification stage: submitting and responding to the reporting process under human rights treaties necessarily imposes a human and financial resource burden.

- Thirdly, at the implementation stage: especially in implementing economic and social rights. Traditionally, these rights are seen to incur an outlay of resources on behalf of the state.

This additional resource burden is seen as too overwhelming and the primary focus of Pacific Island governments tends to be on economic growth and responding to the pressures of an exploding and young population.

Young Pacific Islanders living with disability

Pacific Island countries have a rapid population growth with over half the population under the age of 24 in some countries. Of these, there are almost 360,000 Pacific Islanders living with disability. As a result, young Pacific Islanders with disability are the population group most likely to be living in poverty today and in the future. It is these youth who are the future of the Pacific Island nations.

Less than 10 percent of children and youth with disability have access to any form of education compared with an enrolment rate of over 70 per cent for non-disabled children and youth in primary education in the Asia and Pacific region. This exclusion from education for children and youth with disability results in exclusion from opportunity for further personal, social and vocational development. People with disability also remain disproportionately undereducated, untrained, unemployed, underemployed and poor. As I mentioned previously, economic and social rights such as the right to work and the right to education are not recognised under the current bills of rights of most Pacific Island countries.

This is where the international human rights framework can assist. The Biwako Millennium Framework and the Biwako Plus Five create targets to ensure that people with disability are no longer excluded. Ratification of the CRPD will add an additional layer of protection, legally binding protection for these people. The Convention also assists in the progressive realisation of health, education and other economic and social rights. This approach will assist many people, more than people with disability in each country.

The CRPD and economic growth

Pacific Island countries are primarily focussed on economic growth. However, a recent report by the UN High Commissioner for human rights indicates that economic growth and development have been disappointing in the Pacific and the costs of poor governance have been significant.

What is often not understood about the CRPD is that it 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, who are often among the poorest in any country.

By ratifying and implementing the Convention, governments should see results which will, in fact, assist in the economic growth of their country. Ways in which this may eventuate are through:

- increased workforce participation by people with disability and their family members and carers;
- increased economic participation by people with disability;
- a potential decrease in public expenditure on parallel and specialist services; and
- potential business opportunities in the development of accessible products and technologies and works in the community.

The CRPD can assist because it addresses development including economic development, governance issues and can also attract significant funding. If people with disability in the Pacific are to be included in national development processes, then the development of policy, legislation and service provision must be established in full partnership with organisations of people with disability and other concerned agencies. The Convention can play a key role here, in affirming the rights of people with disability and spelling out the action needed to implement them.

For donors and aid organisations, ratification of the Convention and adherence to the rule of law will improve the public standing of that country and government. Ratification and implementation will also demonstrate to international aid organisations that governments have goals to work towards that are internationally recognised. As international aid organisations are going to be looking at measuring against Convention parameters, ratifying countries will improve their chances of receiving aid.

Pacific perceptions of human rights treaties

There is also a perception amongst Pacific Island countries that international human rights treaties were not designed for small, developing nations. Rather, they are seen as an external political and legal interference. The indigenous traditional power structures in most Pacific Islands are patriarchal and hierarchal. Identity may be tied up with the inherited chiefly system. This system is strongly resistant to human rights intervention as it is seen as a 'Western imposition' on culture and identity.

Added to this, the individualistic nature of human rights is seen to be incompatible with the communal nature of Pacific Island states.

It is hard to make accurate judgments about the ways and extent to which Pacific cultures are inherently unfavourable or favourable to human rights values. They are foreign in as much as they were not thought up in Pacific societies and

Pacific terms. However, this does not mean that human rights should remain foreign to or cannot have applicability in, Pacific cultures.

People with disability represent a significant, overlooked development challenge, and ensuring equality of rights and access for these people will have an enormous impact on the social and economic situation of Pacific Island countries.

As already mentioned, an obvious problem in most Pacific Island countries is that the vast majority of people know little about their constitution let alone their rights under international human rights treaties. They rely more closely on traditional and religious leadership than on their parliamentarians for their daily needs. Therefore they do not have the tools to lobby their leaders to make changes in policies, laws or practices that affect them.

Getting the CRPD ratified

Earlier this year, the Australian Human Rights Commission, through its international membership of the Asia-Pacific Forum of National Human Rights Institutions, did some preliminary work in Samoa — in conjunction with a number of other organisations — to build capacity of NGOs of people with

disability. This was so NGOs would be better placed to advocate to their governments to sign and ratify the Convention. We hope to be able to continue this work in the future.

In relation to advocacy to governments to sign and ratify the Convention, chances of succeeding will probably depend upon the strength of advocacy, and the messages and support that come from as many people as possible.

This is why it is important for people with disability in these countries to familiarise themselves with the Convention. Work plans should be developed around it. It should be referred to when speaking with government and other organisations. People should be educated about it. Adopting such an approach provides direction and focus for activity. It also puts the Convention in the forefront of people's minds.

Finally, what must be remembered is that it is a journey. Ratification is only a small step on the journey to implementing and using the Convention to its fullest.

Note

1. To date Australia, New Zealand and Vanuatu have ratified the CRPD.

The Convention on the Rights of Persons with Disabilities: Why it is needed

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The General Assembly of the United Nations adopted the Convention on the Rights of Persons with Disabilities (CRPD) and its associated optional protocol on December 13, 2006. At its opening ceremony on March 30, 2007, Australia along with 80 other nations and the European Union signed the CRPD. The Convention entered into force on May 3, 2008 and Australia ratified on July 17, 2008. The CRPD negotiations are reputed to have involved the highest level of civil society participation of any human rights treaty. This representation was overwhelmingly that of people with disability and disabled people's organisations (DPOs).

This paper discusses the evolution of the CRPD. In particular it will look at the central role the issue of development played in garnering support for the negotiations and the unprecedented involvement of civil society in negotiations. It will then look at the mechanisms the Convention contains to promote international cooperation and establish a human rights framework for international development programmes.

Disability: The missing component of human rights law

The CRPD is the first UN treaty finalised in the 21st Century and is also the first binding human rights instrument to explicitly address disability. Up until the adoption of the CRPD, disability had been the missing piece of the international human rights framework. Disability has been invisible within the binding international human rights instruments; none of the equality provisions in the International Bill of Human Rights — which includes the Universal Declaration of Human Rights, the International Covenant of Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights — list people with disability as a protected class. The application of these instruments has resulted in disability being recognised within the grounds of 'other status'. Nor does disability feature strongly within the thematic conventions.¹ Disability is not mentioned in either the International Convention of the Elimination of all forms of Racial Discrimination, nor the Convention on the Elimination all forms of Discrimination Against Women, though the treaty body has, through general recommendation 18, required member states to provide data on women with disability in their periodic reports. The Convention on the Rights of the Child (CRC) explicitly refers to disability for the first time in an international treaty. Article 23 of CRC

provides for children with disability to achieve the greatest possible social integration.

This lack of recognition, within the binding instruments of international human rights law, does not mean that the international community has not had a focus on disability in the 25 years preceding the disability Convention negotiations. During those years, the UN and the international community engaged in significant policy and programmatic work to establish non-binding international standards. In 1976, the UN adopted the Declaration on the Rights of Disabled Persons, in 1991, the General Assembly adopted the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, in 1992, it adopted the World Program Action for Disabled Persons, and then followed up in 1993 with the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. Regardless of this extensive policy and programmatic work, the incidences of violations of human rights of people with disability were still of concern. Proposals were brought to the General Assembly on three occasions to develop a convention on the rights of people with disability but failed to generate support with member states.²

Disability and poverty: A vicious circle

An estimated 650 million people worldwide experience disability with two-thirds of that number in developing countries. This is an important fact to consider as people with disability in developing countries are recognised as being overrepresented among the poorest of the poor.³ Poverty is recognised as both a cause and a consequence of disability.⁴ Poverty may cause disability through malnutrition, poor health care, and dangerous living conditions. In developing countries higher disability rates are associated with higher rates of illiteracy, poor nutritional status, lower immunisation coverage, lower birth weight, higher rates of unemployment and underemployment, and lower occupational mobility. The United Nations Educational, Scientific and Cultural Organization estimates that 98 per cent of children with disability in developing countries do not attend school.⁵ Disability can further cause poverty by preventing the full participation of people with disability in the economic life of their communities. Further, children with disability in poor developing countries often have little to no access to health care. Effective strategies to combat diseases such as HIV/AIDS and malaria include the provision of health education,

prevention and promotion; however, this information is often not available in formats accessible to people with varying types of disabilities. Less capacity to adapt to environmental changes in their surroundings, due to lack of information and support systems, people with disability are vulnerable to issues of environmental sustainability. Yet, despite the obvious links between disability and poverty, disability continues to be largely absent from international development efforts. In recognising the important role of development programmes, the Special Rapporteur on disability and human rights, in his 1993 report, cited underdevelopment as a violation of human rights.⁶ The failure of development and international aid programmes to include a disability perspective fundamentally entrenches the exclusion of people with disability from development efforts continuing the cycle of poverty and disability.

Despite the evidence of the significant links between disability and poverty, along with continued evidence that people with disability were among the poorest of the poor, several major UN social development initiatives including the 1995 World Summit for Social Development, the World Summit +5 and the Millennium Development Goals, which were directed at eradicating poverty by 2015, failed to incorporate disability as a mainstream issue.⁷ This failure was recognised by Mexico, which then proposed a convention based on a social development approach.⁸ With this approach, Mexico was able to garner support for a thematic convention on the human rights of people with disability and as such social development was a strong focus of the negotiations.

Getting disability onto the human rights agenda

In December 2001, the General Assembly established an ad hoc committee to consider proposals for a convention. The General Assembly resolution establishing the ad hoc committee called for participation by civil society in the deliberations of that committee. This resolution and the modalities adopted by the ad hoc committee paved the way for an unprecedented level of civil society involvement, particularly, as noted in the introduction, this was predominantly involvement of people with disability and DPOs. The ad hoc committee met in eight sessions over a five-year period. It is estimated that at any given meeting there would have been over 100 people with disability and representation of over 70 national and international DPOs, and including civil society delegates from developing nations.

The mandate given to the ad hoc committee was for the convention to create no new rights with the objective that the convention apply existing human rights within a disability context. Accordingly the chairman of the negotiating committee has conceptualised the CRPD as an implementation convention; one that sets out a detailed code for how existing rights should

be put into practise with respect to people with disability. In achieving this aim, the Convention provides for a mix of non-discrimination and substantive articles and it includes first generation rights, being civil and political rights, and second generation rights, being economic, social and cultural rights.

The CRPD

The CRPD is notably the most detailed statement of human rights by the UN to date. It comprises a preamble and 50 articles. Its articles vary considerably in length, with some articles being a brief statement of rights or principle and others being quite detailed in guiding states in the types of measures that need to be taken to ensure people with disability can exercise their rights. In response to the length of the document, the CRPD is the first human rights treaty to contain titles for each article as an aid to its accessibility.

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. Some of the 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 with which it is necessary to comply in order to fulfill the right. It is effectively an international charter of rights for people with disability. It provides a framework for policy analysis, design and implementation and is a tool for DPOs in advocating for the rights of people with disability. Central to the achievement of this is the general guarantee of the right to equality before the law contained in Article 5 of the Convention and the clear emphasis on the right to non-discrimination including reasonable accommodation of disability requirements.

The Convention contains several innovative elements. 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 Convention contains in Article 3 a list of general principles. These principles include:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- (b) Non-discrimination;
- (c) Full and effective participation and inclusion in society;
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) Equality of opportunity;

- (f) Accessibility;
- (g) Equality between men and women; and
- (h) 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, 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 new formulations of rights, in brief:

- Article 11, situations of risk and humanitarian emergencies;
- Article 19, living independently and being part of the community;
- Article 20, personal mobility; and
- Article 26, habilitation and rehabilitation.

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.

Civil society and the Convention

One of the major achievements for this Convention is the way that it successfully integrated on-going involvement with civil society. This Convention heralds a new formal role for civil society. The CRPD is the first convention to so thoroughly engage civil society in the negotiations and to include substantive provisions outlining on-going engagement with implementation and monitoring. These provisions are embedded in Article 4 General obligations, Article 33 National implementation and monitoring and notably Article 32 International cooperation.

The inclusion of these provisions recognises engagement with civil society as a particularly important part of capacity

building, which is critical in relation to disability. The very nature of disability, and the inherent systemic discrimination and social exclusion that is an element of it, means that many governments have very limited expertise in disability. People with disability have been excluded from key social institutions which has isolated them and the issues that disability raises from mainstream public policy. This was repeatedly demonstrated through the failure of successive treaties to recognise disability as an area of concern. The dominance of the medical model has meant disability has been a welfare or clinical issue within social security, medicine and rehabilitation. Further segregation in education has meant historically low levels of academic achievement, which have kept people with disability out of key professions and public administration.⁹ As a result, people with disability have not been represented in the decision-making process. Disability has not been an area for academic concern in the areas of law, policy, public administration, planning and architecture which has led to limited understanding of the issues raised by disability.¹⁰ This has meant that ever since disability emerged as a significant human rights issue, governments have been slow in implementing remedial programmes.¹¹

Implementing the CRPD

The CRPD has been conceptualised as an ‘implementation convention’ setting out a detailed code for how existing rights should be put into practice. As such it plays an important role in the realisation of human rights for people with disability. A central objective of a human rights approach to development is ensuring that aid programmes further the realisation of human rights. To this end and given the undeniable link between disability and poverty, especially in developing countries, international development initiatives have the potential of being significant implementation mechanisms, and as such it is critical that international cooperation be bound by the principles derived from CRPD and other international human rights instruments. The CRPD provides a template for including a disability perspective in all development initiatives. The human rights standards contained within CRPD should guide development cooperation and planning both of disability specific initiatives and mainstream programming.

The CRPD and international cooperation

The CRPD marks the first time international cooperation has appeared as a stand-alone article in an international treaty. International cooperation issues were robustly promoted within the ad hoc committee meetings. There was a strong push for the recognition that international development programmes needed to be inclusive of and accessible to people with disability. The CRPD provisions build on the elements found in other human rights instruments.¹²

International cooperation, where it appears in other instruments, is formulated as a general implementation method. The working group that drafted the negotiation text proposed a broader approach to international cooperation. Its discussion highlighted that international cooperation should be conceived broadly to incorporate elements such as the exchange of information and best practices, scientific research, training, awareness raising, cooperation between DPOs, the development of technology, and capacity building not interpreting international cooperation as just the transfer of economic resources, economic aid or assistance.

A substantive article, Article 32 International cooperation, along with provisions in Article 4 General obligations and a Preambular paragraph were included in the text. The proposed inclusion of a substantive article in the early drafts of the Convention text generated significant debate. Many states were concerned that this was a significant shift away from existing human rights approaches to international cooperation. States were concerned that such a formulation was inconsistent with previous approaches where international cooperation was solely linked to implementation and not a specific right. Further it was argued that no human rights instrument deals with states' obligations toward other states. There was pressure for any reference to international cooperation to be general rather than specific obligations consistent with previous formulations in international law. Such previous formulations make reference to implementation horizontally not being possible without international cooperation but do not set out obligations. Some delegations considered that a separate article on international cooperation may hinder implementation of this Convention; it would allow states to say the reason they are not respecting the rights of people with disability is because other states have not met their international cooperation obligations.

In the preamble, subparagraph (l) recognises the importance of international cooperation for improving the living conditions of people with disability in every country, particularly in developing countries. This is supported by two other paragraphs (g) that emphasises the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development. While subparagraph (t) emphasises the fact that the majority of people with disability live in conditions of poverty, and in this regard recognising the critical need to address the negative impact of poverty on people with disability.

The Article 4 general obligations includes, in paragraph 2, an overarching provision with regard to economic, social and cultural rights, that each state party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realisation of these rights. This

provision only applies to economic, social and cultural rights and does not in any way waive responsibility of the immediate applicability of civil and political rights.

Implications of the CRDP for international cooperation

Apart from these overarching provisions, CRPD includes Article 32, international cooperation. Article 32 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 CRC 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 also promotes other partnerships with relevant international and regional organisations and civil society, in particular DPOs. It promotes unilateral and multilateral resource transfer including; aid, information, best practice, scientific knowledge, technical assistance and technologies.

If we consider the CRPD in light of Article 32 and the interpretive elements and the general obligations of Articles 4, 5 and Article 9, accessibility, there are clear requirements that become obvious for international aid programmes. Aid programmes need to adopt the principle of equality and non-discrimination to ensure all programmes and services provide equitable and non-discriminatory access for people with disability. Access needs to be recognised as a much wider concept than just physical access. If we consider the provisions within the Convention, access requires not only physical access but also that all aspects of services are provided without discrimination. For people with disability it should include access to information about services in appropriate formats and modes of communication. This would include the provision of any reasonable accommodations people with disability may require. To achieve this end any policy framework should include both horizontal and vertical strategies. This would involve strategic mainstreaming across programmes and projects along with disability-specific measures to address systemic disadvantage and designed to accelerate inclusion and participation of people with disability.

The text of the Convention clearly points to an on-going 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 programme 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.

Notes

- * Some of the general analysis of CRPD is drawn from work previously done in collaboration with Phillip French for the article Kayess, R., and French, P. *Out of Darkness Into Light? Introducing the Convention on the Rights of Persons with Disabilities*, *Human Rights Law Review*. Oxford University Press. 8:1, 2008
1. Other than the Convention on the Rights of the Child (1990) the thematic conventions prior to the CRPD are the International Convention on the Elimination of All Forms of Racial Discrimination (1965); International Covenant on the Elimination of All Forms of Discrimination Against Women (1979), Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1984); and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (1990).
 2. Proposals were sponsored by Italy in 1982 and 1897 and by Sweden in 1989, see Degener, T and G Quinn 2002, *Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability*, UN, New York and Geneva, p30.
 3. Elwan, Ann 1999, 'Poverty and Disability; A background paper for the World Development Report', World Bank, October.
 4. UK Department For International Development *Disability, Poverty and Development*. February, 2000.
 5. Website of the Flagship on Education for All and the Right to Education for Persons with Disabilities: Towards Inclusion, <www.unesco.org/education/efa/know_sharing/flagship_initiatives/disability_last_version.shtml>, (accessed January 20, 2009).
 6. 'UN Sub-Commission on Prevention of Discrimination and Protection of Minorities, *Human Rights and Disability: Report by Special Rapporteur: Leandro Despouy*', U.N. Doc. E/CN.4/Sub.2/1991/31, UN Sales No. E92.XIV.4 (1993).
 7. See further, Annan, K 2000, *We the Peoples: The Role of the United Nations in the 21st Century*, UN, <www.un.org/millennium/sg/report/ch2.pdf>, accessed 13 November 2007. See also, *The Statement Of The Millennium Development Goals And Disability Africa Regional Conference, Nairobi, Kenya 15th To 17th September, 2008*, *The Statement Of The Millennium Development Goals And Disability Africa Regional Conference, Held At The Panafric Hotel, Nairobi, Kenya 15th To 17th September, 2008* accessed January 20, 2009.
 8. The sponsors of Resolution 56/168 Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities were Bolivia, Chile, Columbia, Congo, Costa Rica, Cuba, Democratic Republic of the Congo, Dominican Republic, Ecuador, El Salvador, Guatemala, Jamaica, Mexico, Morocco, Nicaragua, Panama, Philippines, Sierra Leone, South Africa and Uruguay.
 9. Linton, S 1998, *Claiming Disability: Knowledge and Identity*, NYU Press, New York.
 10. Ibid. See also Barnes, C, G Mercer and T Shakespeare 1999, *Exploring Disability: A Sociological Introduction*, Polity Press, Oxford.
 11. Bengt Linqvist 1995, *Standard Rules in the Disability Field – A New United Nations Instrument in Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments*, Theresia Degener and Yolán Koster–Dreese (eds), p:63-68, Martinus Nijhoff Publishers, London.
 12. UDHR, General Comment No. 5 of the Committee on Economic, Social and Cultural Rights; *The Standard Rules* (rule 22).

Making disability policy in the Pacific rights-based policy

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Pacific social policy context

Traditional languages, cultural beliefs and practices which do not recognise people with disability as having the right to full and fair participation and access to services in their communities, represent a significant barrier to developing rights-based disability policy in the Pacific. A 'critical collaboration' approach has proved effective in developing inclusive language and in turn enabling the development of policy responses to the needs of people with disability and in promoting partnerships between community-based organisations and government social policy agencies.

In all cultures the family is the 'heart' of society and culture. In Pacific Island countries the family extends its influence through a structure that is large and complex. The family is the principle economic and political unit, welfare agency, and dispenser of justice. As with all other societies, these relationships and roles are rapidly changing with urbanisation and the extension of education, health and the monetised economy.

Traditional structures and authorities are being challenged by these changing social arrangements, as well as by the increasing risks that high rates of diabetes, hypertension, road accidents and other non-communicable and communicable diseases present. Although the figures are not comprehensive or reliable, the Pacific, with the rest of the world, is likely to have an incidence of disability of 10 per cent (United Nations 1990) or more in the general population.

This group also tends to be over-represented among those people living in poverty as they seldom have income earning and livelihood opportunities. When there are few services or public support programmes, political leaders refer to the family as principle welfare and support agency.

If disability policy is to have an impact, change attitudes, set standards, and identify priorities for addressing needs, then the policy development process itself must be taken to the village and developed within this social and cultural context. Such an approach has been termed 'critical collaboration' because it is based on collaboration between government and civil society and it engages people with disability and the community in writing policy. As Riley (2008:15) noted, 'such efforts are often volatile, fragile and ... call for change and cooperation among all involved'.

The critical collaboration approach brings people into the centre of policy making by mainstreaming their needs and voice across sectors, and addressing social cohesion both locally and

nationally (see Ortiz 2006). In this context, policy development can be transformative and gives substance to the saying: 'nothing about us without us.'

Political recognition of people with disability in the Pacific

Why should governments willingly cooperate and make policy for people for whom they provide few services? Why should they bother about a minority group who are rarely seen and who rarely feature as a priority in national development plans? Governments, traditionally, have not concerned themselves with this group. If disability is not recognised as a priority in the national development plan not only does the government ignore this group but donors and other regional development partners do as well.

A United Nations Economic and Social Commission for Asia and the Pacific (ESCAP) survey of progress with implementing the priorities of the 1993-2001 Asian and Pacific Decade for the Disabled Person received a poor response from Pacific governments. Those that did reply to the survey questionnaire illustrated that few of the decade's priorities were being addressed and that people with disability had not been considered a part of national (and regional) development processes.

People with disability had been largely ignored and excluded from national development planning and priorities. Given the high incidence of diseases such as diabetes, the increasing number of car accidents and lack of early intervention services, the number of people with disability in the Pacific is likely to be high in comparison with other regions of the world.

Despite the apparent high prevalence of people with disability in communities there is a lack of community awareness, services, policy guidance and recognition that people with disability have rights equal to all in society. The needs, aspirations and concerns of people with disability had been swept under the proverbial Pacific mat.

When political leaders or officials are asked who will address the needs of people with disability, the common response is: 'the family'. However, families often keep their family member with disability at home and do not necessarily promote or advocate for their rights or access to services. In some situations, children with disability are a source of shame and are excluded from school and community activities.

There is often a lack of acceptance of people with disability within families, communities and schools.

Where government does not provide services, this does not mean it has no role to play. If the quality of life of people with disability is to be improved, the central place and role of the family, church, NGOs and other community-based organisations requires government recognition and the development of strategic partnerships between the state and civil society. Policy has a role to address equity and rights issues as well as to organise this relationship, and set principles, standards and priorities.

Pacific social policy lacks an adequate broad-based framework to provide an understanding of social processes and how they are changing. Social policy in the Pacific context is defined in terms of education, health, housing, or welfare with little recognition of the relationships between these sectors and little acknowledgement of how one may impact on the other. Pacific governments have relied on the traditions embedded within families and villages and have assumed that traditional practices will continue to address the needs of people and, in particular, the special needs of vulnerable groups.

The Biwako Millennium Framework

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) was endorsed by the Pacific Islands Forum leaders meeting in 2003. It is designed as a rights-based tool for governments to guide policy development, planning and implementation of programmes concerning people with disability.

The BMF has explicitly incorporated the Millennium Development Goals (MDGs) and their relevant targets to ensure that the concerns of people with disability are an integral part of the MDGs and national poverty alleviation strategies.

The BMF's goal is to promote inclusive, rights-based societies free of barriers for people with disability in the region. To achieve this goal, the BMF's mission is to strengthen the following priority areas:

- self-help organisations and related family and parent associations;
- women with disability;
- early detection, early intervention and education;
- training and employment, including self-employment;
- access to built environments and public transport;
- access to information and communications, including assistive technologies; and
- poverty alleviation.

Seven Pacific Island countries (Cook Islands, Kiribati, Federated States of Micronesia, Fiji, Papua New Guinea,

Solomon Islands and Vanuatu) recently developed national disability policy statements using the BMF model to guide the policy development process. Four governments have formally endorsed the policy and two have committed additional resources to implement the policy. A further three Pacific Island governments have indicated a wish to develop new policy within the next few months.

The BMF is proving a useful tool for guiding the policy development process and ensuring that debate on priorities is situated within the community. In addition to shifting attention away from welfare provision to giving recognition to the rights of people with disability, the BMF redefines disability as arising from barriers in society preventing the full inclusion of people in the community and national development processes. The focus of attention is shifted away from the welfare of the individual and onto recognising and addressing societal barriers and human rights. The BMF provides the framework to start a discussion about disability that gives a clear message our concern is not simply individual and welfare based, but one that involves all of society.

Many Pacific Island countries are now using definitions of disability that address the environmental barriers that create a disabling society, and draw on this WHO (nd) definition:

Disability is the outcome of the interaction between a person with an impairment and the environmental and attitudinal barriers he/she may face.

In the case of Fiji, for example, the community took the WHO definition of disability and applied their own understanding and agreed, through an iterative policy development process undertaken in almost all of the provincial centres, on their own definition:

People with disabilities are those who cannot fully participate in everyday life and society effectively, due to environmental and attitudinal barriers, as well as owing to physical, psycho-social, sensory and other impairments and who, because of their lack of inclusion in village life and society generally, do not enjoy their full human rights as citizens and participants in communities and families (Fiji Government 2006).

Many community meetings grappled with the meaning of disability and the process stimulated a debate about how it is understood within the community and what kind of vernacular can be employed to talk about disability. Although the WHO definition may not have been fully embraced, it was recognised, particularly in respect of situating people with disability within communities and acknowledging their right to participate in all aspects of community life.

The consultation process

Only when all have had an opportunity to mould and influence the policy document and priorities is there a sense of ownership and commitment. This process is iterative and involves a wide range of stakeholders in formulating, debating and agreeing on the key elements of the policy. Consultation elicits community priorities and those priorities are reflected in a set of agreed goals and objectives, as well as strategies and actions sufficient to ensure the goals and objectives are met.

A further consequence of policy consultation, involving open discussion and information sharing, is that it builds alliances and enhances collaboration and coordination. It also increases understanding of the issues, raises awareness and goes some way to identifying and recognising that people with disability have the same set of 'rights' as others in society. Most importantly, national disability policy development must ensure that those who have disability have a say.

Policy consultation also builds awareness in the wider community that the issues are not isolated, that similar concerns exist elsewhere in the world and that disability is, in fact, a global concern. The policy development process provides the opportunity to draw together the threads of international and regional commitments made by government, with other national policies and priorities, to form a coherent national policy statement.

The policy development process has followed a similar path in many Pacific Island countries. In most cases the process has been preceded by a national scan of policies and survey of people with disability in order to build a clear rationale. There has always been extensive consultation with disability stakeholders (i.e. people with disability, families and care givers as well as service providers including churches and NGOs), initially to draft the policy, followed by community consultations to build on the draft policy through an iterative process that develops a dialogue about the meaning of disability and the aspirations of people with disability.

Model policy, based on the BMF, provides a vehicle for governments and communities to build rights-based discourse and express the rights and needs of people with disability within a broad community-based framework.

Participants of the Pacific Islands Human Rights Consultation (2004),

reaffirmed that the primary focus for the promotion and protection of human rights is at the national level and that therefore it is the primary responsibility of States to ensure that human rights are respected, promoted, protected and fulfilled.

The meeting also acknowledged that 'all governmental bodies must play an important role in protecting human rights.'

Indian MP, S Jaipal Reddy, draws a distinction between a rights-based approach to public policy at the national or local level, and a rights-based approach to development cooperation. He has noted that although a rights-based approach to public policy is most desirable, it needs to come from within.

Reddy says that movement away from political, economic or social oppression can only be sustainable when it springs from within a society and is in harmony with local culture and values. Reddy argues that rights which are externally driven do not necessarily represent the interests of local communities (Nyamu-Musembi and Cornwall 2004).

Conclusion

The development of effective public social policy requires consultation with local and national stakeholders. The idea that vulnerable groups and individuals should play a central role in policy formulation targetting them gives greater certainty the policy is relevant, able to be implemented and will work for communities, families and individuals as well as government and church agencies, NGOs, private sector employers, schools and tertiary training institutions. The key to developing good social policy is recognising that although the policy may target particular vulnerable groups, such as people with disability, the response to meeting the needs of the target group is to engage with the whole community. The agreed policy objectives must reflect the interests and priorities of all community stakeholders if more inclusive societies are to develop, barriers dismantled and human rights recognised.

The way we respond to the most vulnerable in society says much about the society. Although some Pacific Island countries address disability concerns in their national development plans, very few have set specific objectives and made disability a priority.

The BMF has grown out of the Asia and Pacific experience, reflects the priorities which governments in this region have articulated and provides a framework for disability policy development at the national and community level. A number of Pacific Island countries have taken this framework and developed national policy and an action plan through participatory processes.

The benefits of such processes include building capacity, developing commitment, awareness and recognising human rights within a social and cultural context. The BMF has encouraged the development of inclusive language and challenges established traditions in the way disability is perceived. Moreover, the policy development process has engaged those who have a stake in articulating priorities and the means of addressing those priorities. In this way, policy is rooted in the everyday world and concerns of people with disability as they live in rural villages and urban communities throughout the Pacific.

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AusAID: Inclusive development: A new era in consultation

Kristen Pratt, Director, AusAID Disability Taskforce

I'm proud of the consultation process. It has been quite exceptional in that it put people with disability, their organisations, their families and their carers, at the centre of the process — *Bob McMullan, Parliamentary Secretary for International Development Assistance, at the presentation of the first draft of AusAID's strategy Development for All: Towards a disability-inclusive Australian Aid Program 2009-2014.*¹

A long process of advocacy on the part of those involved in disability and development in Australia drew to a close with the launch of the strategy on 25 November 2008 at the Australian Institute of Sport, Canberra. *Development for All* is the Australian aid programme's first strategy to explicitly include and focus on the needs and priorities of people with disability. The depth of support and commendation with which its development has been met underlines the commitment and passion of those engaged in this area. It also draws attention to the fact that many policies are developed differently — often due to lack of time and forethought, admittedly, but in the absence of broad consultation, and most especially, without listening to those who have most at stake.

The *Development for All* strategy is a product of the Australian Government's social inclusion agenda, which draws on the premise that all citizens should be able to recognise their full potential and have the opportunity to live a rewarding social and economic life, and share in their nation's prosperity. It was also a response towards meeting our obligations under the United Nations Convention on the Rights of Persons with Disabilities (CRPD), both its framework for promoting the wellbeing and supporting the rights of people with disability, and (through Article 32) its call for countries' to work together through international cooperation to ensure the Convention is put into practice.

From the start, the challenges of including people with disability in development were stark — how to avoid the common trap of doing development for, rather than with, the beneficiaries? The struggle to fully integrate gender, HIV and other key development issues into the aid programme confirmed that innovative thinking, time and effort would be needed to move AusAID towards disability-inclusive development. The way we approached this issue from the start would set the scene to how we would move forward. Overall, we think we're on the right track. In comparison with many policy development processes, the development and consultation process of

Development for All was unique in its openness and inclusiveness, and in its determination to ensure that the voices of people with disability were heard and responded to.

This paper sets out the development process for the strategy, both to mark the significance of this historic first step towards a disability-inclusive Australian aid programme, and to enable lessons to be drawn for similar processes. The process has, we believe, reaped real benefits: a sense of investment and trust on the part of stakeholders who will be most directly affected, and a framework for action that is both dynamic and relevant for people with disability.

Planning and preparations: Where did we start?

Clear mandate from the top

To some extent, AusAID's Disability Taskforce, charged with managing the development of the new strategy, was exceedingly lucky. We started with what every team leader or director of new policy initiatives dreams of: clear and strong direction; commitment and ongoing support from the highest level; and political commitment. At the same time, we were given the autonomy and flexibility to manage the process as we saw fit: acknowledging our expertise as disability-inclusive development practitioners.

The mandate for such a strategy was clear. The Australian Government promised during the election campaign that if elected, a comprehensive disability strategy to guide Australia's aid programme would be a priority. The aid programme's strategy affirms the Government's commitment to extending the benefits of development to all, to promoting the dignity and wellbeing of people with disability, and to supporting them to improve the quality of their lives through accessing the same opportunities for participation, contribution, decision making and economic wellbeing as others. It is a part of the broader transformation of Australia's aid programme and the Australian Government's social inclusion agenda towards more inclusive, barrier-free and just societies for all.

The taskforce's role in leading the strategy development process was also greatly strengthened by dedicated senior AusAID management understanding of the issues and support for the process.

The right team

Having the right mix of people in the team facilitating and pulling the strategy together was critical to getting a good

outcome; it meant that we had in-depth practical understanding of the issues and credibility with our stakeholders.

The branch head overseeing the process had prior experience in local government in the development of a social justice policy. The director of the taskforce, originally trained as an occupational therapist, had 15 years of work experience domestically in the provision of services for children and young adults with intellectual disability, as well as time in Papua New Guinea working with local NGOs supporting people with disability prior to joining AusAID. Two of the inclusive-development policy officers on the team also had direct professional and personal experience with disability. One member is a person with a disability, new to AusAID and with a substantial legal background in human rights instruments as well as experience in a developing country working on a disability-related activity. The other inclusive-development policy officer, also an occupational therapist, has 11 years work experience in disability and development in Maldives, India and PNG. Another member of the team had extensive experience in managing the development of a similar strategy process on a complex and sensitive issue and had worked closely with a large and diverse stakeholder group in the process. The team's coordination and support officer had a family member with a disability who had been deeply involved in the local community in relation to services for people with disability.

This sound mix of skills and experience was complemented by two consultants recruited to support the taskforce and who provided invaluable support early on in the process. The taskforce was clear about what they wanted from the consultants and roles and responsibilities were clarified at the outset. The consultants brought with them an important mix of technical experience and expertise in relation to performance measurement in the preparation of a strategy and a sound understanding of the trends, issues, and key stakeholders in inclusive development internationally. Both consultants had directly relevant personal experience; one of the consultants had a background as a physiotherapist working with people with disability and the other was a parent of children with disability.

Another key role for the consultants was in leading the in-country discussions with stakeholders. This was important in the countries where the disability taskforce facilitated consultations because it provided some distance between the 'AusAID face' and the stakeholders, and enabled stakeholders to express their views freely and firmly. The consultants could simply listen impassively without the need to present or defend a government position.

Importantly, the consultants were flexible and responsive in their approach to the work of the taskforce and, in addition to agreed inputs and deliverables, were available to provide support and advice on specific issues as they emerged. At no time did

they attempt to dictate or drive the process — their approach was to facilitate and provide support and advice as needed, and in response to where the taskforce and process was at and the issues at hand.

Planning and being realistic

We recognised that the approach to developing the strategy was as important as the final product, in terms of building understanding of the issues and establishing credibility for AusAID in the way it set out to meet the Government's new direction — disability-inclusive development — for Australia's aid programme.

We carefully mapped out what we believed to be a comprehensive and realistic process, making best use of all resources available, and then sought a revision of the original time frame set for the process, which gave us a further two months to carry out the consultations. The revised time frame gave us the time that we needed to make best use of available resources, both internal and external. This included working with the Australian Disability and Development Consortium and other partners such as the Pacific Disability Forum and NZAID. It also allowed us to properly reach our key stakeholders and have sufficient time with them, to research what other partners were doing in this area, to collate, synthesise, and analyse information and to test it with stakeholders and revise and refine as we went along.

Review of lessons learned

We undertook research and analysis of other donors' efforts, lessons learnt and AusAID's own programmes. Lessons learned from other donors confirmed what we suspected: that disability-inclusive development was challenging, 'mainstreaming' had not been a success, and many organisations continued to struggle to make headway.

Key stakeholder needs

We took time to map out who the most important stakeholders were, what we needed from them, what competing priorities or challenges they might face in considering the issues, and then set out to structure the process to make it as easy as possible for them.

For instance, we mapped out a clear process for the Minister for Foreign Affairs and Parliamentary Secretary for International Development Assistance. This included critical decision points for Government. We provided regular updates throughout the strategy development process.

We structured discussions with people with disability, in places where they were comfortable, and tried to distribute background information, including key questions, to them in accessible formats ahead of time to give them time to

consider and discuss the issues. Where possible, discussions were translated into the local language or an interpreter was engaged. Understanding each group's level of understanding of the issues was also important in how we approached issues, and it brought them along in the process. We wanted to make sure that we properly heard from people with disability, what their priorities were, and how they felt that AusAID could best support them.

At the same time, we knew that whatever the shape of the final strategy, if AusAID staff didn't understand and support it, then it would be challenging to effectively implement. We recognised that AusAID officers have busy work programmes and competing priorities and aimed to minimise additional work for them around the process. For those AusAID country officers who facilitated consultations, we provided 'consultation kits'; tools to provide them guidance and practical information, tips and strategies to make the job as easy and comfortable as possible, allowing our colleagues to learn about the issues during the consultation process.

Through the consultations, many 'AusAIDers' had their first experience in directly relating with a person with disability. Supported by the consultation guidelines or after having sat through the process with the taskforce, most people came away far more confident about spending time with people with disability. In addition, most could immediately see opportunities for including people with disability in AusAID's programme.

We included representatives from Disabled People's Organisations (DPOs), Australian NGOs working in the area of disability and development, and other key partners such as NZAID in the development of the process from the outset and kept them informed and sought their advice at key stages throughout.

'Nothing about us without us'

This widely-quoted saying is used to communicate the idea that no policy should be decided by any representative without the full and direct participation of members of the group(s) affected by that policy, particularly groups that are often thought to be marginalised from political, social and economic opportunities. 'Nothing about us without us' relies on the principle of participation, and has been used by DPOs globally to achieve the full participation and equalisation of opportunities for, by and with people with disability. We listened to and respected this principle and deliberately put people with disability, their families, carers and representatives at the forefront of the process from the outset.

Scope of and approach to consultations

Consultations informing a disability-inclusive strategy for Australia's aid programme took place in the majority of

developing countries Australia works with, and with leading disability and development stakeholders in Australia during July and August 2008. Stakeholders included people with disability, their families and carers, government representatives, NGOs, service providers and other donors.

AusAID, in conjunction with prominent regional, Australian and international organisations, including a regional DPO and donor partner, prepared a Disability Strategy Consultation Paper to help guide discussions during the consultation process. This paper was widely distributed before the consultations and was available electronically on AusAID's internet in a range of accessible formats. It was also translated into local languages where needed. Many stakeholders commented on the value of the consultation paper, the issues raised, and the opportunity to simply sit with others and consider and discuss the issues. By itself, this reflective process started to build joint understanding of issues.

AusAID's Disability Taskforce led consultations in Samoa, Vanuatu, Thailand, Laos and East Timor and observed consultations in the Philippines. Consultations led by AusAID posts took place in 14 other countries. Public meetings for Australian stakeholders were held in Sydney and Melbourne. Two small focused events were held for leading disability stakeholders from the region and Australia to enable them to directly brief Australia's Parliamentary Secretary for International Development Assistance on priorities identified through consultations.

Responsibility and ownership

It was recognised that occasionally AusAID either hasn't had the internal expertise or time to dedicate to comprehensively manage and maintain ownership of a process for a new initiative such as this. The taskforce felt that allowing consultants to take a key role in the development of the disability strategy could come with risks that: AusAID might not fully comprehend the issues behind the final product, not entirely agree with or support it, or lack ownership of it when moving to implementation. Part of the strategy development process in our minds was building awareness, understanding and capacity and as such, AusAID needed to be actively involved in the process. The consultants respected and supported the taskforce's expectation that AusAID would be the primary architect of the strategy.

Providing balanced support

The taskforce was mindful of two competing situations during the strategy development process: the need to provide timely effective technical support as needed to bolster confidence, capacity and success of AusAID personnel in engaging in and supporting the development of the strategy while avoiding

a longer-term situation where disability-inclusive practice in AusAID was viewed as being the primary responsibility of a disability-inclusive team.

Our ultimate goal is for all AusAID staff to have the understanding, commitment, skills and resources to ensure that people with disability are automatically and effectively included in their standard development processes, and that they benefit equally from AusAID's aid programme. So it was important to strike a balance of providing the appropriate level of support in a manner that clearly left responsibility with the relevant area.

Existing capability in AusAID

In addition to the taskforce team members, we soon found that there was considerable depth of interest and experience in disability-inclusive development among many AusAID staff members and these officers were quickly able to engage in the strategy development process and immediately apply their understanding of the issues to their core AusAID work.

The taskforce took advantage of this group. Identifying, acknowledging and working with these AusAID staff members greatly strengthened the strategy development process, and contributed to further building ownership of the strategy within AusAID.

Trusting the process

Although we had some broad parameters that would guide us and some issues that we wanted to explore, we kept an open mind about what form the strategy might ultimately take. We allowed the strategy to evolve in response to the issues arising throughout the process and undertook a continual process of 'testing' the themes, approaches and priorities with our primary stakeholders throughout the process, reviewing and refining as we went along.

The first full draft of the strategy was subjected to a rigorous peer review process and was endorsed by the AusAID Executive and Minister for Foreign Affairs before being presented by Mr McMullan for final consideration at the International Conference 'Disability, Disadvantage and Development in the Pacific and Asia', in Canberra at the end of September 2008, where many people who were consulted in the strategy consultation process were present.

In allowing the consultation process to inform the development of the strategy we reached a point with the final document where we were confident that key stakeholders could clearly see how the issues that they had raised during the process had been addressed; either included or if not, why not. A key to this was using language and phrases often used by key stakeholders. Final revisions involved strengthening the language which led to a change in the sub-title of the strategy to 'Towards a disability-inclusive Australian aid program', a

stronger emphasis and greater clarity around the relation of the CRPD and the strategy, a stronger focus on the links between disability and poverty, and the inclusion of vocational training under the strategy's support for inclusive education.

Remaining flexible and responsive

Given the tight time frame that we faced in consulting, analysing and drafting the strategy, we needed to adhere to a tight and comprehensive work programme to meet the deadline. The in-country consultations were demanding, in terms of the pace of meetings, time to reflect and write up of meeting outcomes, and often back-to-back travel programme. We were also confronted with a growing level of interest in the issue among the public and within AusAID. We needed to prepare briefings for ministers and respond to correspondence with AusAID and ministers on the issue.

It would have been tempting, given the need for precision timing, not to have been flexible and responsive during the consultation process. However, taking advantage of opportunities that came up and varying in our approach undoubtedly strengthened the process. For example, supporting the Pacific Disability Forum, the Pacific Islands Forum Secretariat, the Fiji National Council for Disabled Persons and the Fiji Disabled Peoples' Association to facilitate a workshop with stakeholders in Fiji on behalf of AusAID. This variation to the original work plan, while requiring some extra effort on our side, ultimately resulted in one of the most inclusive and comprehensive parts of the consultation process. We found that it was important to remain open to these types of opportunities and be willing to do a rapid cost/benefit analysis before deciding not to proceed with a different approach.

Information management

One of the biggest challenges — after dialoguing, clarifying and recording information in face-to-face meetings — was consolidating and analysing all of the information coming in various formats, in a very short time period, and working through how we treated the information, how would it inform the strategy, or not. Simple systems to group issues and prioritise them assisted with this process, making it easy for us to discuss and form decisions about how to use information in the strategy design. For example, the decision not to refer to a 'mainstreaming approach'. While ultimately we are aiming for disability-inclusive development to be mainstreamed in AusAID, it was clear to us that the use of the term would prove both confusing and off-putting and would not assist the positive implementation of the strategy.

Transparency and accountability

Throughout all stages of the consultation process, many stakeholders explicitly commended AusAID on the participatory

and open approach taken in developing the strategy. People with disability and their families told taskforce members throughout regional consultations that they were heartened to have their views explicitly sought out and to have 'space' in which they felt genuinely listened to. We heard from NGOs, AusAID staff, advisors, consultants, and many others that the consultation process was 'something different'. And, that this was 'very new and refreshing for AusAID'.

By the time the Parliamentary Secretary presented the draft strategy it was, by and large, enthusiastically supported by stakeholders at the conference. Key to arriving at this point was maintaining a high level of openness and communication throughout the process, keeping stakeholders engaged and informed of our thinking and developments throughout, so that what was presented for final comment was not new to them. We hope that stakeholders felt that their views were heard and treated seriously and with respect.

We are committed to maintaining this approach throughout the implementation, monitoring and evaluation of the strategy.

Lessons learned

On reflection, there are a number of things that we could have done differently. The process might have been strengthened had there been greater representation by stakeholders from remote and rural areas. Many involved felt that a longer time period was warranted to do justice to the task, but we found it important

to make best use of the available time, people, expertise, etc. This process was particularly effective because of the ability of the team to work with what we had, and remain dynamic and open and responsive to all possibilities.

The needs and priorities of people with disability vary from country to country as well as within countries and communities, and any strategy risks ignoring some and privileging others, or remaining at so high a level as to fail to speak to people's needs.

We are determined to see the strategy implemented in such a way as to make its objectives and principles real. In the foreword to the strategy Mr Stephen Smith, Minister for Foreign Affairs, and Mr McMullan confirmed this commitment with the following clear and simple statement:

There are many good reasons why we must do more to support people with disability to meet their full potential; social reasons, economic reasons and building better communities for all. But the most compelling reason is the most fundamental: it is simply the right thing to do.

Note

1. From the Parliamentary Secretary's presentation of the first draft of AusAID's strategy *Development for All: Towards a disability-inclusive Australian Aid Program 2009-2014* to the Australian Disability and Development Consortium's International Conference on Disability, Disadvantage and Development in the Pacific and Asia on Monday 29 September 2008.

New Zealand official development assistance for disability

Megan McCoy, New Zealand Agency for International Development

Introduction

Agencies responsible for managing official development assistance (ODA) develop policy frameworks which outline their approach to human rights issues, including disability. These policy frameworks then inform programming initiatives and advocacy engagement. The approach and implementation are crucial in determining whether disability is appropriately recognised or becomes an invisible issue.

The experiences of the New Zealand Agency for International Development (NZ Aid) in managing the New Zealand Government's ODA, in the Pacific in particular, via the policy framework, can provide lessons learned on both the approach and implementation of the framework as it relates to disability.

The policy frameworks of national development agencies responsible for managing ODA provide the strategic direction, modality and guidance for providing both financial and advocacy (or policy engagement) support. The development of these policy frameworks is informed by multiple factors including the situation within partner countries, international 'best practice', domestic context, political relationships, international obligations, and the particular expertise and passion of agency staff.

The process for developing those frameworks is crucial in ensuring a balance between multiple influential factors. And clarity between approaches, especially as they relate to human rights, is vital in informing implementation through funding and advocacy. This can involve a rights-based approach, mainstreaming and/or specific human rights focused initiatives.

Official development assistance

Mainstreaming human rights in development aims to ensure that human rights principles are a foundation for all ODA activity — through development policy, programmes and organisational systems. While the degree to which human rights is included can depend on the context and purpose, effective mainstreaming ensures that human rights are appropriately and consistently considered.

Disability, as an essential human rights issue, sits within the mainstreaming approach and can be seen as a strategy for achieving equality for people with disability. Mainstreaming disability can be seen as a similar process to mainstreaming gender where the concerns and experiences of people with

disability are integral to all phases of policy and/or programme (from design to evaluation) as they relate to political, economic and societal spheres (ECOSOC 2007:2-3).

In moving forward with the mainstreaming of disability, it is also important to learn from the experiences of mainstreaming gender. This includes ensuring that responsibility for mainstreaming rests at the highest levels within agencies, making certain there are accountable measures for monitoring progress and bearing in mind that mainstreaming does not negate the need for specific initiatives (ibid:8).

The need for specific initiatives for disability is recognised in the development of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). While the Convention does not establish new rights per se, it recognises that:

a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities will make a significant contribution to redressing the profound social disadvantage of persons with disabilities and promote their equal participation in the civil, political, economic, social and cultural spheres with equally opportunities, in both developing and developed countries (UN nd:Preamble y).

Specific initiatives are also documented in the Biwako Millennium Framework (BMF) for Action towards an Inclusive, Barrier Free and Rights-based Society for Persons with Disabilities in Asia and the Pacific. The BMF's principles/policy directions include establishing/strengthening national coordination committees on disability and supporting the development of people with disability and their organisations (UNESCAP 2002).

The specific approach to human rights (including disability), and other relevant factors (such as senior organisational leadership and guidance for staff), determine whether it is appropriately considered, or becomes an invisible issue.

NZAID policy framework

NZAID is a semi-autonomous body within the Ministry of Foreign Affairs and Trade (MFAT) responsible for managing the New Zealand Government's ODA. As a relatively new agency, established in 2002, its overall policy framework is still to some extent in the development and implementation phase. NZAID's vision is a safe, just and inclusive society, free of poverty.

NZAID has been required by Cabinet to mainstream human rights, along with gender and the environment. This requires human rights to be considered across all policy and strategy, programme and organisational culture and processes.

As a core human rights issue, disability is considered across a range of policy and strategic documents. A review of these documents, from the MFAT Statement of Intent down to the NZAID Pacific Strategy, shows that disability is referred to as a human rights issue that requires the development of a mainstreaming approach, a cross-cutting issue as part of human rights, or an issue that requires a multi-sectoral approach within health initiatives.

The NZAID health policy, however, most notably supports a twin-track approach, which aims to address fundamental inequality as well as supporting specific initiatives to enhance the empowerment of people with disability. It also advocates for the participation of people with disability in public policy dialogue, development and implementation.

There is a clear mandate to mainstream human rights, with implications in considering disability across all policy and strategic work. There are, however, a number of key guiding documents which do not provide any acknowledgement of disability, and multiple interpretations where it is mentioned.

While it is important for each policy to consider the unique outcomes it is trying to affect, it is difficult to consider how any development policy or strategy cannot consider the particular situation for people with disability who do, after all, make up at least 10 per cent of the world's population. What is more, 80 per cent of the world's people with disability live in developing countries (WHO 2005).

Implementation of the NZAID policy framework

The NZAID policy framework is implemented through programmes that deliver ODA (including funding and advocacy). These can be bilateral, regional, multilateral or contestable/criteria-based schemes. Each programme has some form of guiding strategy; the process for developing it will depend on the type of programme. For bilateral programmes this involves a negotiated process with the partner government, which is often based on the national development plan.

Regional programmes are often guided by the strategic processes and/or plans of the region. Within the Pacific, this includes the ministerial meeting processes, which are largely managed by the Pacific Island Forum Secretariat. For other programmes, this can involve a balancing of the thematic context with the unique perspectives of NZAID, that is, where value can be added.

These strategies guide the programmes over a multi-year timeframe. As strategic documents, they do not specify each

project the programme will support, but rather set out the rationale for the priority directions. These directions are then implemented through agreements with a variety of partners, from government to civil society, for the delivery of programmes and/or projects.

Programme strategies are informed by a situational analysis, which recognises three forms of poverty: extreme poverty, poverty of opportunity and vulnerability to poverty. People with disability within developing countries often suffer from all these forms of poverty. The evidence suggests that people with disability are often disproportionately represented among the poor and are also often poorer than citizens without disability. It is estimated that of the world's poorest people, one in five is a person with disability (Elwa 1999).

While very few NZAID programme strategies include specific references to disability there is considerable support to specific initiatives and increasing attention to mainstreaming disability.

NZAID support to specific initiatives

NZAID supports specific initiatives such as the Pacific Island Forum Secretariat, the Pacific Disability Forum, and the national disabled people's organisations (DPOs).

Some of the major lessons learned from NZAID's support to specific initiatives are related to supporting organisations that are often new or challenged through inexperienced and under-resourced capacity. For any official development agency, managing the domestic accountability requirements can put pressure on to supporting well-established organisations with robust project and financial management systems that work towards a clear strategic direction.

Many disability-focused organisations are staffed by volunteers and have never had the experience of dealing with donor requirements, so the challenges can often seem insurmountable. When NZAID has made the decision to support those organisations, there has sometimes been insufficient up-front consideration of the depth of capacity-building support required.

The most challenging aspect of supporting the capacity development of any organisation is ensuring that technical advice, whether from NZAID or contracted consultants, facilitates the organisation and individuals to complete the tasks themselves. While some disability-related activity has been carried out by consultants, the agency is now moving back to supporting organisations with a mandate, such as national disability councils.

This recognises that while NZAID is required to consider efficiency, it must also consider sustainability and effectiveness in any development activity. This approach requires a long-term investment, such as providing funding for assistive technology.

While the accountability requirements cannot be relaxed for DPOs, capacity-building support can be increased to ensure equity with other NGOs.

NZAID has also had to reconsider some of the processes that we take for granted. This means ensuring all hard copy contract documents are accompanied with an electronic version.

While there can be challenges in implementing specific initiatives, sometimes the challenges lie in identifying that specific initiatives are required in the first place. The Pacific presents unique challenges in this respect.

With a total population of over eight million spread over a vast area of ocean, the populations of the Pacific vary both between countries and within country islands. While it would be desirable for every Pacific country to have the same range of support services and advocacy groups that developed countries may have, the economies of scale often mean this is impossible. This can require some creative thinking about the modalities for support to people with disability. No matter how small the population, each person with disability is both a rights holder and duty bearer.

Recent internal reporting on human rights activity did not accurately reflect the full complement of activities related to disability. For some reason, staff didn't naturally associate the disability-related activity within their programmes as part of the human rights reporting. It was apparent that programme staff require support to embed disability as a fundamental human rights issue.

NZAID mainstreaming of disability

Mainstreaming, by its very nature, can be difficult to quantify. NZAID does not as yet have indicators for the mainstreaming of human rights, let alone disability. While the agency health policy notes that a mainstreaming approach to disability will be established over time, this guidance has not yet been developed.

While NZAID is required to mainstream human rights and disability across all development activity, the Sector-Wide Approach (SWAp) can provide some insight into how this might work at national level.

A SWAp commonly involves the coordination of development support from a range of partners around a national sector plan, for example health or education. It aims to enable more analytical and strategic management of development assistance in a holistic approach, and away from the high transaction costs comparative to outcomes associated with individual projects.

The education policy and strategy, for example, recognises that education is a human right and should therefore ensure inclusive and equitable access, including a particular emphasis on 'disability-inclusive measures'. The reality is that very little to date has been proactively followed through on this (for various reasons) within SWAps. In some countries government has been

solely focused on getting the majority of school children into quality education, so little resourcing has gone into supporting those children with disability.

While this is not entirely dependent on NZAID's (or other development partners') financial or technical support, the reality is that there has been no guidance for staff on what disability-inclusive measures are and how they might be included within the SWAp modality.

Despite this, there are positive signs that disability is becoming an increasingly important focus for education. The Pacific Regional Initiative for the Delivery of Basic Education (PRIDE) is reporting significant grants to countries to support inclusive education.

One NZAID bilateral programme also reported that increased attention was being placed on education for children with disability in the next strategic phase. A large majority of the basics in rebuilding an education system were completed or underway, and the partner government 'owned' this new direction, which is expected to lead towards sustainable outcomes. In addition, many of the initiatives to date had supported a more accessible education system in general, so specific initiatives for children or young people with disability would be able to build on this.

Moving forward

As a relatively small agency, NZAID also needs to consider the economies of scale question that partners in the Pacific also ask themselves. For an agency that has just started to develop the last of its key policies, it is unlikely that NZAID will have a disability strategy in the near future. What is clear is that some consistency is required in the policy framework as it relates to disability, the mainstreaming approach to disability is developed and that the lessons around both specific initiatives and mainstreaming are promulgated across the agency.

A recent report produced in conjunction with a 'NZAID Guideline on Mainstreaming Human Rights' found that within NZAID, like other donors, the 'internal organisational barriers to mainstreaming appear to outweigh the (often difficult) contexts of development'. In the context of an internal structural review process, NZAID is considering resources across the board. It is hoped this will result in greater capacity for the mainstreaming of human rights, and thus disability.

The 'NZAID Guideline on Mainstreaming Human Rights' is also a positive development, providing guidance for programming staff on the implementation of activities which highlight issues the agency has committed to mainstream (including human rights) and other cross-cutting issues.

This tool provides specific guidance on mainstreaming across sectoral programmes, including education. It also specifies that

supporting DPOs at national level is one way of supporting advocacy of the rights of people with disability, including holding government and other agencies accountable. It is hoped that specific guidance will also be developed which identifies further key issues specific to disability mainstreaming.

There are also plans to improve information sharing across the agency regarding support to disability, including specific and mainstreamed initiatives. So that at the very least, staff embarking on a programme of support for, or impacting on, people with disability can identify colleagues to learn lessons from their experiences.

There is likely to be increasing attention placed on both the NZAID policy framework and its implementation by a range of stakeholders. New Zealand NGOs working on disability issues have become active in further developing an NZAID contestable scheme to ensure disability is appropriately considered in the application, and hence design, implementation and evaluation processes. Setting the standard for one scheme could lead to further engagement across NZAID's processes.

With civil society partners in the Pacific in disability moving from strength to strength, it is not inconceivable that attention could eventually end up on the policies and implementation activities of donors such as NZAID. The recent commitment of the Australian Agency for International Development (AusAID), aside from the significant financial support and the development of a specific disability strategy, has already served to draw more attention to this area by government and civil society partners alike. While NZAID has been one of the few official development agencies working in disability in the Pacific, there is a need to ensure that the agency is able to learn from the experiences of AusAID as they embark on implementation of a draft disability strategy.

In moving forward it is important to remember the commitments NZAID has to disability outside the existing policy framework. For the first time in 2008, NZAID provided input into the MFAT reporting to the Office for Disability Issues on the New Zealand Disability Strategy. Reporting back in future years will ensure that NZAID is meeting New Zealand Government expectations regarding disability. The recent third High Level Forum on Aid Effectiveness, which resulted in the Accra Agenda for Action (World Bank 2008:13(c)), states:

Developing countries and donors will ensure their respective development policies and programmes are designed in ways consistent with their agreed international commitments on gender equality, human rights, disability and environmental sustainability.

While the Millennium Development Goals (MDGs) do not include specific reference to disability, the high numbers of

people with disability has a considerable impact on whether the MDGs will be met (ECOSOC 2007). This adds to the impetus to follow through on policy commitments.

Perhaps most importantly, New Zealand ratified the CRPD on 25 September. Article 32(1) of the Convention states that:

States parties recognise the importance of international cooperation and its promotion, in support of national efforts for the realisation of the purpose and objective of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, partnership with relevant international and regional organisations and civil society, in particular organisation of persons with disabilities (UN nd).

While NZAID already considers that its existing policy framework is aligned to the Convention, there is likely to be additional emphasis on the implementation of the policy framework in light of the commitments embodied in Article 32.

Conclusion

The NZAID policy framework and the implementation of this have led to support to both disability-specific initiatives and the mainstreaming of disability across other development activity. For the Pacific region in particular, NZAID has supported disability-specific activity across a number of countries and the region.

With the added emphasis on disability, it is timely for NZAID to consider both the consistency and appropriateness of the policy framework as it relates to disability and the implementation of these policy commitments. One of the most important considerations in moving forward is analysing the tools and support that the core programme staff, responsible for developing programme strategies and implementing activities, require to enable them to effectively consider disability (as is required by the mainstreaming approach) across the design, implementation and evaluation of all development activity.

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Getting the word out: Developing, communicating and using international conventions

Robyn Hunt, New Zealand Human Rights Commission

Introduction

It can be no accident that there is today no wealthy developed country that is information-poor, and no information-rich country that is poor and underdeveloped
Dr Mahathir Mohammed, former Prime Minister of Malaysia.

Access to information is fundamental both to development and to the realisation of human rights for everyone, including people with disability. Without access to information and communications, there would be little progress or prosperity. Access to information is a fundamental right under the Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights. Knowledge of rights is fundamental to being able to realise them and perform our obligations as citizens.

While ignorance of the law is no excuse, in a free and democratic society governments generally recognise their obligations towards their citizens to provide information about the law. Fundamental civil and political rights mean that information from government to the public must be accessible so people can exercise their civil and political rights, their rights to official information and access to justice, and so on.

It can be argued that in relation to civil and political rights the right to information should be realised immediately. There is also an obligation to make progress in the areas of information provision for economic social and cultural rights.

This paper gives a brief overview of the role of accessible information, education strategies and programmes, and communications using a variety of channels and strategies in development and capacity-building initiatives which focus on the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

There are cost implications for creating accessible information. However, in my experience, accessibility is more about attitude than about technical knowledge and expensive technology. With the right approaches and appropriate plans the best value can be achieved with available resources.

International support for access to information

As well as clear direction given in the CRPD, access to information and communications including information,

communications and assistive technologies is also one of the seven priority areas identified for action in the Biwako Millennium Framework.

Access to information is very clearly elaborated in Article 9 on accessibility, and Article 21 on freedom of expression and opinion and access to information in the CRPD. While the CRPD does not grant new rights in this respect, it does give clear guidance on how this right should be realised.

The CRPD equates access to information with access to buildings and transportation, which is significant. The right to information is generally described as a desired outcome rather than in technical terms so flexibility is appropriate in implementation. Access to information is threaded through 14 of the 32 non-procedural articles of the Convention which define accessibility mandates, some of which are specific, some implied.

Access to information will be absolutely necessary for the involvement of people with disability and their organisations, and for civil society generally in working towards ratification of the CRPD, and for the implementation and monitoring of the Convention.

People with disability and their organisations will need to use a variety of strategies to spread the word. Spreading the word about the CRPD began in the earliest stages of its development. People with disability began to mobilise to support the Convention from day one. They had at their command one of the most powerful communication tools ever developed — the electronic media.

Electronic media and developing the CRPD

The CRPD is an historic document in a number of ways. Not only is it the first human rights instrument of the 21st century and the fastest to be negotiated and adopted by the UN and subsequently come into force, it was also the first to involve NGOs, and in particular disabled people's organisations (DPOs) in the negotiations. All of these 'firsts' relate to the use of the internet.

The internet enabled the formation of the powerful alliance of DPOs, the International Disability Alliance (IDA). It enabled these organisations to negotiate and form positions between meetings of the ad hoc committee, learn about and from each other, distribute action alerts, advocate to politicians and government officials and diplomats, gather support from people with disability at home and from other NGOs. It enabled information to be cheaply and speedily distributed and meetings

organised and conducted online. It enabled people and groups who could not afford the expense of regular trips to New York to participate in some way.

Daily reports on the UN negotiations could be posted and detailed feedback from home organisations, experts and other influencers could be received overnight ready for the next day's proceedings.

These advantages also worked for governments, although they would have always had access to more communication resources than NGOs. National human rights institutions were also able to take advantage of the internet and they formed working groups and quickly produced influential papers without needing to physically meet.

This work continues with the Asia Pacific Forum of National Human Rights Institutions forming an international partnership to progress human rights for people with disability.

Adoption and ratification

Following adoption of the CRPD, a plethora of websites has sprung up offering usually free and often quality resources about the Convention. Blogs provide excellent opportunities for posting and commenting. There are also online education packages and advice on strategies to encourage governments to ratify. National human rights institutions such as the New Zealand and Australian Human Rights Commissions and the Asia Pacific Forum of National Human Rights Institutions have posted resources and information about the CRPD.

The UN has also produced online resources and information relating to the CRPD and disability rights. During the negotiations in New York, the UN was challenged to produce information in accessible formats, and needed to build an accessible website for the CRPD and resources relating to it. Sadly, much of the rest of the UN website remains impenetrable.

Standards and accessibility

All of this activity raises the question of international and national standards for accessibility of websites. International best practice, which forms the basis of many government standards, is developed by the Web Accessibility Initiative of the World Wide Web Consortium (W3C).¹

There are many resources on the web which can provide assistance with website accessibility. Many mainstream, and some disability development organisations, could greatly improve the accessibility of their websites and their valuable free downloads if they are serious about providing accessible information for people with disability.

Even in developed countries the accessibility of government websites is far from universal. It is critical for standards worldwide to improve so people with disability have equal access to information.

DPOs in developing countries can advocate for the development of government standards based on international best practice to make sure their governments are providing accessible information, which is a very cost-effective way to do so in the long term. The CRPD and the relevant sections of the Bwako Millennium Framework are useful tools here.

Development neither is, nor should be, a disability-free zone, so if disability is to be mainstreamed into development it should be introduced at the earliest stages of technological development in an integrated fashion, and not left solely to disability-focused organisations to progress, where there is a danger of it becoming a technological ghetto.

Disability-focused, mainstream development agencies and international technology-focused organisations should look for opportunities to work together to bridge the digital divide. If mainstream development organisations, and, for that matter, disability-focused organisations, really want to include people with disability and their issues, they must make their information accessible to people with disability to enable them to contribute to the process.

Productive partnerships

Technology is enormously valuable, but building relationships is also an important strategy. During the development of the Convention, the New Zealand Government and officials worked closely with people with disability, forming a productive partnership. This partnership gave wide access to briefing documents and position papers, and pooled expertise for the best possible results.

Following completion and signing of the Convention, this partnership was renewed to work towards ratification.

While good relations with government officials are necessary to get things done, it is the politicians who must be convinced that action is needed. People with disability and their organisations can be sources of regular, reliable and trustworthy information. They can produce ideas for solutions, and case studies to illustrate both problems and solutions.

This approach can help allay fears about costs in relation to implementation of the Convention. Those working with government and officials need to be well informed and briefed. Talking points can be prepared in advance and copies provided. Questions can be anticipated and answers produced. Strong community support will also help reinforce these relationships.

Communication planning

The development of the CRPD has resulted in local, national, regional and international coalitions among disability organisations and other organisations with human rights agendas. Networking among NGOs and sharing information

is increasing, and becoming easier. Training for advocates can be sourced and adapted through regional and international networks.

Public attitudes and support from wider civil society as well as from people with disability and their organisations may also be mobilised in support. Communication planning will be important. Who needs to be engaged and how? What outcomes are being sought? What are the obstacles and the strategies to overcome? Key messages can be concise, positive and clear. Audience and key messages can be identified and matched.

One of the most useful ways of gaining community acceptance is for all of those involved to interact in various ways on an equal basis. Getting to know each other, talking to each other and working together on a human rights issue of mutual benefit and importance and challenging stereotypes and discriminatory attitudes in a real situation makes a difference. Respectful coalitions on issues of mutual concern may provide better outcomes than working alone.

Making information accessible

Organisations, local, national and international, which recognise the importance of including *all* people with disability in their development or other work, can take some basic steps to begin with.

Firstly, people need vital information, such as the text of the CRPD in their own language. This should be a given in any situation. Alternative formats such as audio, Braille or sign language will be most useful when they reflect people's language, nationality and culture.

Some useful principles to begin the process of developing accessible information are:

- universal design concepts must underpin all activities;²
- policies and standards should be based on international best practice in whatever medium is being used;
- responsibility for accessible information must be defined and allocated — accountability is key;
- involve people with disability from the outset — nothing about us without us;
- accessibility has to be planned from the start, adding it in later won't work and will cost more;
- accessible information and communication must relate to and contribute to the business goals of the organisation so people understand why, and the rationale will be clear and justifiable;
- clearly identify and understand the audience/s and the means of communicating with them;
- make accessible formats available at the same time as the information is available to everyone else so

people feel valued;

- information is provided through the range of channels and formats your audience needs — not everything may need to be produced in every format on every occasion;
- accessible formats should be provided to the same content and professional standard and quality as 'regular' formats;
- clearly signpost the formats and channels so people know what is available and how and where to get it to ensure resources are not wasted; and
- producing multiple formats may need multi-disciplinary teams so that all the expertise needed is involved.

Alternative formats

While traditional printed material can be made more accessible than it often is by following best practice guidelines, an increasing number of alternative formats for traditional print materials are available. The spread of digital technologies has provided new, often cheaper and more varied accessible media, such as audio description for video and film.

This area changes rapidly. Technologies which used to be highly specialised such as audio books can be downloaded from the internet and are becoming more mainstream.

Alternative formats include large print, Easy Read (which is different from plain language), digital audio files such as WAV and MP3, Braille, CD-ROM and DVD. The least expensive to produce is large print produced in-house to best practice guidelines, the most expensive is Braille.

Some of these are now available via the internet, an example being files downloaded to computers with refreshable Braille displays. Others, such as large print and Easy Read, have wider audience appeal than for people with visual or intellectual impairments, respectively.

People who are deaf or hearing impaired need alternative formats to access purely audio information. Captioning for video programming, as well as text transcripts of audio files are the usual means. This applies to files on websites, intranets and on CDs, DVDs and computers.

Many of these formats require a variety of resources and are not practical in all situations. Available technology can be used creatively, such as text messaging on mobile phones. Development of sign language and provision of Braille for blind children to develop their literacy are essential.

Campaigns and social marketing

New Zealand's 'Like Minds Like Mine' social marketing campaign to counter stigma and discrimination against people with mental illness has been a measurable success.³ While it has

been a campaign with high profile television advertising, which meant it was not a cheap option, social marketing can take many forms and in this case included high-level participation by people with experience of mental illness.

The campaign also includes a speakers' bureau, print resources (some in Pacific languages), research publications, and merchandise. The training manuals, fact sheets, posters, postcards, videos, and CDs can be used in workshops, seminars, classes and events to enhance information and educate people about the importance of reducing the stigma and discrimination faced by people with experience of mental illness.

Working with the media

Establishing good rapport with the media is important. It may assist in engaging the wider community in changing attitudes towards a human rights-based perspective. In smaller communities, working with the media is often relatively easy.

Making sure you and your organisation are well informed about issues at local national and international level will mean you can become a trusted source. Knowing and meeting their deadlines is critical, and choosing the 'angle' for a story relating to a particular issue is important. The more help you can give the media, the more they will like it

Education strategies and programmes

There are a number of education tools and approaches which can assist with community building and spreading understanding about rights.

Training people with disability to train others to educate their peers was a strategy used in the USA following the introduction of the Americans with Disabilities Act, and in New Zealand following the inclusion of disability in the Human Rights Act of 1993.

The *Tu Tikanga*, Rights Now! programme for people with disability, and the *Korowai Whaimana* programme for people with experience of mental illness have been

successful in educating people with disability about their human rights.

These programmes have contributed to a more sophisticated understanding of human rights generally among people with disability in New Zealand. This has been evidenced by the way the disability community called for an inquiry into accessible land transport and then participated in the inquiry process.

Peer to peer education is a useful community tool for building knowledge of human rights among people with disability. It is particularly valuable for building support among groups of people in similar situations and with similar experiences. It can provide a safe place for sharing stories, learning together and gaining confidence to take the next step. It is important that any programmes start with the current situation of the participants, and move on from there at the pace of the group.

Nothing about us without us

I have tried to demonstrate throughout this paper the leadership role that people with disability have taken in the development of the CRPD. This critical role must be continued and strengthened. Without people with disability playing leading roles in the ratification, implementation and monitoring of the Convention, human rights will be a purely academic discourse, and we will not be able to demonstrate human rights-based development processes leading to human rights-based societies.

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3. See <http://www.likeminds.org.nz/>

Towards inclusive development: Moving forward in addressing disability in the Pacific

Setareki S Macanawai, Pacific Disability Forum

Disability services in the Pacific

Disability services were introduced to Pacific Island countries between the 1960s and 1980s. Much of the initial services fell under the responsibility of civil society organisations, church groups and concerned individuals within the private sector who wished to address the needs of children with disability. Subsequently, numerous single and cross-disability NGOs were established in the Pacific region. They mainly focused on the provision of special education and rehabilitation services, were managed by non-disabled persons, and adopted the view that people with disability must be cared for, spoon fed, protected and segregated. People with disability were regarded as recipients of good will and unable to make their own choices or determine their own destiny.

Traditionally, a strong extended family system in most Pacific Island countries encourages family members to look after less fortunate relatives. But a disabling condition has long been associated with an ancestral curse, parental misdeed, witchcraft, shame and fear and this has kept people with disability isolated, neglected, dependent and poor. Furthermore, the struggling economies of these island nations have inhibited government attention to the presence, needs and concerns of their disabled population.

In the 1990s, some positive developments in the area of disability services began to emerge as various Pacific governments and disability-related organisations implemented the targets and actions of the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) Decade of Disabled Persons, 1993-2002. The theme and goal of the decade was the promotion of the full participation and equality of people with disability in the Asia and Pacific region. The decade's agenda for action provided a framework for the following: national coordination, legislation, information, public awareness, accessibility and communication, education, training and employment, prevention of causes of disability, rehabilitation services, assistive devices, self-help organisations, and regional cooperation.

Thirteen of the 20 UNESCAP Pacific island member states became signatories to the Proclamation on the Asian and Pacific Decade of Disabled Persons. Some Pacific Island countries which did not sign the Proclamation, Papua New Guinea, for example, nonetheless took an active part in some activities. Others that did sign, including the Marshall Islands, Tuvalu, Federated States of Micronesia, Palau and Niue took little or no action.

In May 2002, a decision was taken by governments of the UNESCAP region to extend the Asian and Pacific Decade of Disabled Persons for another decade, up to 2012. In October 2002 a high-level intergovernmental meeting to conclude the Asian and Pacific Decade of Disabled Persons was held in Japan and representatives from Fiji, Samoa and Cook Islands played a prominent role in the meeting, along with a representative from the Pacific Islands Forum Secretariat. The highlight was the adoption of 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 is the policy document to guide decision making and action to achieve an inclusive, barrier-free and rights-based society for people with disability in countries of the UNESCAP region by 2012. An inclusive society means a society for all including people with disability; a barrier-free society means one that is free from physical and attitudinal barriers, as well as social, economic and cultural barriers; a rights-based society is one based on the concept of human rights, including the right to development.

This regional disability framework encourages governments to actively implement the paradigm shift from a charity-based approach to a rights-based approach to the development of people with disability and to move towards the human rights perspective, especially the perspective of the right to development for people with disability. The BMF identifies seven priority areas for action:

- self-help organisations of people with disability and related family and parent associations;
- women with disability;
- early detection, early intervention and education;
- training and employment, including self-employment;
- access to built environments and public transport;
- access to information and communications, including information, communications and assistive technologies; and
- poverty alleviation through capacity building, social security and sustainable livelihood programmes.

According to Wilkinson (2005), people with disability in Pacific Island countries are among the poorest and most marginalised members of their communities. They are

uncounted, unheard and their rights to development, full participation and equality are not upheld. They lack education, employment and livelihood opportunities, and have no or limited access to support services, leading to their economic and social exclusion.

Lack of awareness and understanding in the wider community has meant that people with disability and their families face prejudice, discrimination and rejection in their daily lives. This view was shared by government representatives from 12 Pacific Island countries who attended the UNESCAP 7th Special Body on Pacific Island Developing countries in Thailand in 2002. An assessment of achievements made by Pacific Island countries during the first Asian and Pacific Decade of Disabled Persons showed these countries lagged behind in the implementation of the decade's agenda for action. This lack of progress was attributed to lack of information, distance and cost of travel, poorly performing economies and lack of government commitment.

Pacific Island countries had made progress in a number of the priority areas, however, particularly with national coordinating committees, legislation, information, public awareness, education, prevention of causes of disability, rehabilitation, self-help organisation of people with disability, and regional cooperation. Little progress was made in the areas of accessibility, training and employment and assistive devices (Nowland-Foreman and Stubbs 2005).

Political will at regional level

With disability awareness gaining momentum in the region, the Pacific Islands Forum (PIF) Secretariat began to show keen interest and explore effective ways of engaging in this emerging social issue. Miller (2007) commented that disability was not on PIF's agenda until 2002 when the then Prime Minister of Vanuatu, Edward Natapei, raised the issue for the first time at a Forum meeting in Fiji. This move was prompted by recommendations adopted by UNESCAP's 7th Special Body on Pacific Island Developing Countries Meeting in Bangkok in 2002.

The PIF Education Ministers' meeting in 2002 also considered issues in basic education for children and youth with disability, resulting in the inclusion of this concern in the Forum's Basic Education Action Plan. Furthermore, an issues paper relating to disability in the region was presented at the pre-forum session of the Forum Officials Committee in New Zealand in 2003 resulting in disability finding its place in the 2003 PIF communiqué. Therefore, the BMF was endorsed by PIF leaders, providing a lasting mandate for regional work in the area of disability.

The leaders acknowledged that immediate priorities for Pacific Governments should be to address policy that would

dismantle barriers and improve access and coordination for people with disability. Honouring its commitment to this sector, PIF's Secretariat organised a Pacific regional workshop on disability in Fiji in 2005. The establishment of the Disability Coordination Officer position at the PIF Secretariat in 2006 was again a clear indication of Forum leaders' commitment to the issue.

UN support

A number of Pacific offices of UN organisations have also worked to address disability issues in the region. UNESCAP's Pacific Operation Centre (UNESCAP/POC) actively promoted the Decade of Disabled Persons, as well as the BMF and its supplementary document, Biwako Plus Five. It also provided valuable technical assistance to countries such as the Cook Islands, Federated States of Micronesia, Fiji, Kiribati, Papua New Guinea and Solomon Islands in the development of their national policies on disability. UNESCAP/POC has provided valuable contributions in addressing the issue of inclusive education for vulnerable groups, including children with disability, through two regional seminars, in Samoa in 2005 and in Fiji in 2007. UNESCAP/POC also organised a regional training workshop on accessible information and communication technology for people with disability in 2006.

The International Labour Organization (ILO) and UNESCAP/POC have supported disability development in the region in the areas of training and employment, as well as children and youth with disability. The United Nations Development Program has actively promoted issues concerning people with disability, including the funding in 2007 of a desk review on the status of women and girls with disability in the Pacific. The Office of the High Commissioner for Human Rights has supported the promotion of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in the region.

The Pacific Disability Forum

In the 1990s, disabled people's organisations (DPOs) were actively operating in Pacific Island countries such as Fiji and Solomon Islands. Their collective efforts in promoting and advocating for equality, empowerment and participation of people with disability soon gained momentum as other Pacific Island countries established their own national DPOs to be the voice and representative of people with disability.

In March 2000, DPOs in Australia, Fiji, New Zealand and Solomon Islands (all members of Disabled People International) established a subregional office in Suva, Fiji to strengthen self-help initiatives at the national level through leadership training as well as information exchange across

countries in the Pacific. As a result, national DPOs were established in Cook Islands, Kiribati, Samoa, Papua New Guinea, Tonga and Vanuatu.

The Pacific Disability Development Network was established in 2001, with the support of Inclusion International. Under the leadership of Inclusion International, surveys to collect accurate data concerning people with disability were conducted in countries including Cook Islands, Samoa and Kiribati.

The combined efforts of national DPOs and other service providers in the Pacific led to a meeting in Fiji in 2002 where the idea of setting up of a Pacific-based regional organisation on disability was discussed. It was at this meeting that the Pacific Disability Forum (PDF) was born. It continued as a loose organisation until 2005, when an NZAID review of disability support in the Pacific recommended a five-year plan for clear, strategic assistance. PDF was well placed as a partner to NZAID, and the PDF regional office was established in Suva in January 2007.

Resources provided by NZAID have been vital in securing representation and ensuring participation of Pacific people with disability in the regional forums of the UN regional inter-governmental bodies, the governments of the region, and regional civil society organisations. The office is currently organising and supporting the development of a federation of people with disability in the region. The federation will disseminate information, resources and projects to people with disability and their organisations in the Pacific island nations. It is also hoped that through this regional instrument, the voice of people with disability in the Pacific will not be ignored in regional and international forums.

The way forward: Challenges and constraints

From charity/welfare to rights-based

Being deeply rooted in the charity and medical models, disability services in the Pacific are experiencing significant pressure from the disability movement, as well as current global trends and practices in the disability sector. A paradigm shift from charity and medical models to social and rights-based models of disability is both necessary and inevitable if Pacific Island countries are to provide equal opportunities, greater recognition and better treatment of their citizens with disability, as well as to comply with the recently adopted CRPD, the Asian and Pacific Decade of Disabled Persons policy framework, and disability-related instruments adopted agencies such as ILO, UNESCO and UNICEF. The challenge will be for governing boards of service providers and professionals to be 'on tap rather than on top' and where the empowerment of, and self-determination by people with disability are central to policies being developed and decisions being made. National DPOs must also equip themselves with appropriate knowledge and skills to fulfil this role.

Disability-inclusive policies

Pacific Island governments must demonstrate their commitment to the implementation of the BMF, BMF Plus Five and the CRPD by adopting an inclusive approach to disability development and related initiatives in their countries. National development plans, pertinent policies and programmes must be cognisant and inclusive of the needs of people with disability, their families and organisations.

The situation of people with disability in the Pacific is expected to improve as more development partners begin to recognise the need for disability-inclusive practices in their development policies, programmes and agendas. However, disability advocates including national DPOs must continue to advocate to their respective governments for the benefits and cost-effectiveness of disability inclusive plans, policies and programmes.

Disability: A regional priority

The years old call and aspirations of Pacific people with disability for a regional organisation was realised to some extent by the establishment of the PDF. The active involvement of the PIF Secretariat in disability is an important step towards the development of a regional disability strategy. However, the vast distances between island nations of the Pacific makes the frequent participation of member representatives from those countries in regional and international disability-related meetings extremely expensive.

The needs, problems and perspectives of people with disability in this part of the world are rarely, if at all, adequately addressed in such gatherings. Yet, these people with disability are the most in need of assistance and attention, given their isolation from mainstream efforts at rehabilitation and the ongoing struggle for equalisation of opportunities for people with disability. In addition, the young governments and struggling, tiny economies of the region contribute to the lack of adequate services for people with disability as disability issues are often not considered a priority.

However, recent collaborative efforts of various UN agencies, PIF Secretariat, Pacific Disability Forum and other regional civil society organisations to address specific concerns in the field of disability such as inclusive education, vocational training and employment, human rights and theological education are positive steps towards the embracing of disability as a regional concern.

Pacific-specific strategies

The number of people with disability in Pacific Island countries is relatively insignificant when compared with

Asia. More often than not, disability initiatives designed for and undertaken at the Asia-Pacific regional level do not take into account the unique needs of the Pacific. The sudden visibility of disability and increased activities in this sector in Pacific Island countries, particularly in the last five years, has been the result of Pacific-specific strategies. In the much bigger and more complex region of Asia and the Pacific, it is quite easy for the voice, representation and concerns of the Pacific to be lost and dominated by their Asian counterparts.

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Disasters are always inclusive: Vulnerability in humanitarian crises*

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Worldwide there are an estimated 600 million people with disability, approximately 80 per cent of whom live in developing countries, according to the World Health Organization (2005). This represents between seven and ten per cent of the global population. When disasters and emergencies strike, they leave a huge legacy of serious impairment and injury (physical and psychological) further increasing the number of people with disability in affected areas.

In the aftermath of the Indian Ocean tsunami of December 2004, it is estimated that across the Asia Pacific region the number of people with disability increased by 20 per cent (World Bank 2005). Despite these realities, an often heard remark among local and international NGOs and public actors involved in humanitarian action is: 'We didn't see any disabled people; there weren't any ...'

This *invisibility* is a major factor why those with disability are seldom included in the various stages of disaster response or consulted in disaster preparedness measures. But whereas people with disability are at risk of exclusion from humanitarian response, disasters are without partiality. People with disability are among the most vulnerable groups in emergency situations sustaining disproportionately higher rates of morbidity and mortality, at the same time being among those *least* able to access emergency support and essential services such as medical care, water and sanitation facilities, and safe shelter.

Why are people with disability more vulnerable?

Due to limited mobility, many people with disability are isolated or left behind when any kind of disaster strikes. They may lose their mobility device, making it difficult for them to leave home and seek assistance. After the 2007 Bangladesh flood, for instance, and in direct response to the mobility and assistive-device needs of people with disability, Christian Blind Mission's (CBM's) partner, Bangladesh Protibandhi Kallyan Somity (BPKS), distributed white canes, crutches, hearing aids, wheel chairs, artificial limbs and low trolleys to more than 1,100 people.

After the Indian Ocean tsunami, only 41 of the 102 residents of the Sambodhi Residential Home in Galle, Sri Lanka, survived as many were unable to leave their beds or failed to comprehend in time the need to escape. When forced or able to leave their homes, people with disability may find emergency facilities, such as first aid stations or emergency shelters, are inaccessible

because of distance or difficult physical terrain. The surrounding physical environment is often transformed by the destruction caused by earthquakes or floods or by the insecurity of conflict situations, exacerbating further the challenge of mobility and access. During the conflict in Sierra Leone many children with disability were abandoned by their families forced to flee across the countryside (IFRC and RCS 2007).

General distributions to a disaster-affected population cannot necessarily be assumed to reach people with disability. Nor can it be assumed that they will automatically have equitable access to supplies of food, water and non-food items in shelters, internally displaced persons or refugee camps. Being often hidden from view and stigmatised by families and communities, people with disability face exclusion from basic entitlements and services.

Bangladesh flood shelters are traditionally overcrowded while toilets and water sources are inadequate and inaccessible. Families with mobility-restricted adults have found it difficult to pacify other survivors especially when those with disability have no option but to defecate in their makeshift beds. Since many shelters are in closed warehouses with limited ventilation, others blame them for adding to the stench and often gang up, eventually forcing many to leave. Trauma-induced emotional distress and mental illness or even people with disability's own view that they are incapable of participating in relief schemes, can also be limiting factors to their receipt of assistance.

Social support networks are of crucial importance. Many people with disability are dependent on family or close neighbours for their daily needs and livelihood. For example, children with disability may need parents or relatives to take them to school or women with disability may rely on relatives to assist them with domestic tasks. Men with disability may be dependent on their families for their livelihood. Those with visual impairment often have to rely on external assistance with orientation and physical mobility.

Emergency situations tend to escalate this reliance on primary care givers and support structures. If they are disrupted (those they rely on being fully occupied with their own survival and basic needs) or destroyed (injury or loss of care givers), this can result in distress, neglect and isolation with negative impacts on the health and wellbeing of those with disability.

In developing countries, the economic reality associated with disability plays a major part in increasing vulnerability in

emergency situations. The vicious cycle linking disability with extreme poverty is a result of societal and institutional barriers, discrimination and resultant exclusion from education and livelihood opportunities. The poorest often have limited or no access to health care, education, shelter, safe employment and social services increasing the risk of disability developing, or existing impairments worsening.

People with disability are in a very real sense 'doubly' vulnerable when emergencies occur both on account of their impairment and poverty. After the December 2007 post-election violence in Kenya, more than 800 clients with disability who had received loans through CBM's partner's micro-finance programme (APDK), had to close their businesses and were unable to repay. They required food aid and other assistance to sustain their livelihood throughout the crisis.

Disability is often viewed through an unfavourable lens as in many countries there is an association with negative cultural and religious beliefs. A lack of knowledge about disability and the capacities of people with disability even within their own family and the wider community often means they are viewed as being of lower worth and can be ill-treated. In emergency situations, these negative attitudes, whatever their origin, are exacerbated and there may be an increase in violence, sexual abuse and neglect towards those with disability, especially of women and children, by their family and community. After the 1995 Kobe earthquake in Japan, people with intellectual disability who managed to get to shelter faced discrimination from the other occupants and found themselves pushed to the back of food queues (IFRC and RCS 2007).

Despite good intentions, disaster response and rehabilitation efforts typically do not meet the specific needs of people with disability. The inadequate policies and practices of communities and agencies providing humanitarian assistance means they are all too often ignored and neglected at all levels of disaster intervention from preparedness through to rehabilitation. This increases the risk of their marginalisation and exclusion when emergencies occur. Furthermore, the diversity of people with disability is often overlooked in terms of their capability, differences and in the gendered and age-related aspects of their disability or injury.

Inclusion of disability in humanitarian action

Disability should primarily be understood within the context of human rights — the rights of citizens with disability being the same as those for all community members. The Universal Declaration of Human Rights has been signed by virtually every country worldwide and underpins the philosophy and mission of most relief and development agencies. Yet disability has largely been ignored when human rights are under scrutiny. The physical and psychological discrimination many people

with disability suffer is not typically considered alongside other human rights violations such as ethnic cleansing, imprisonment or torture. Relief agencies can therefore easily overlook the rights of those with disability to access emergency support and essential services when humanitarian crises occur.

The UN Convention on the Rights of Persons with Disabilities (CRPD) now constitutes the crucial human rights instrument of international law, allowing claims that will reinforce equality and the full participation of people with disability. Article 11 (UN nd) specifically targets situations of risk and humanitarian emergency by saying that:

States Parties shall take [...] all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

The recent ratification by the 20th state triggers into force the Convention and its Protocol on 3 May 2008. The CRPD will be a powerful tool to eradicate the obstacles faced by people with disability and is a historic moment in the quest for realisation of universal human rights for all.

The Sphere Project's *Humanitarian Charter and Minimum Standards in Disaster Response* (2004) emphasises disability as a cross-cutting issue and the need to target and include people with disability in emergency response. It identifies the key vulnerable groups as women, children, older people, *disabled people*, people living with HIV/AIDS and ethnic minorities. Sphere advocates for special care to be taken to protect and provide for all affected groups in a non-discriminatory manner and according to their specific needs.

The international disability movement has adopted the *social model* of disability as an alternative to the traditional medical approach, which asserts people are disadvantaged by the limitations imposed on them by the *attitudinal, social, cultural, economic and environmental* barriers to their participation in society, rather than by their impairments. A person's disability results from the interaction of their impairment with these barriers preventing equal participation in community life, discrimination and social exclusion.

Many international and local NGOs and agencies now incorporate the language of the social model into their programmes, advocating an inclusive, participatory approach in both longer term development and emergency relief. Despite the adoption of the CRPD and the policies and guidelines that now exist, the challenge remains to operationalise them in ways that are genuinely participatory, ensuring people with disability are fully included, not ignored or merely consulted, in all phases of the planning and implementation cycle.

Best practice recommendations

In terms of meeting the needs of people with disability before, during and after disasters, there is growing guidance and experience to now draw on. Of fundamental importance is their inclusion, along with their families, communities and local disabled people's organisations (DPOs), at each stage of disaster response.

A twin track approach is recommended, whereby disability is prioritised for inclusion into all aspects of disaster programming activity as a cross-cutting issue (similar to the issue of gender) being coupled with the raising and addressing of the *specific and special needs* of people with disability. Such an approach has been shown to also improve the situation of other vulnerable groups such as the elderly, children, pregnant women and the extremely poor.

Commencing at the disaster preparedness stage, the centrality of a community-based disaster planning approach can not be over emphasised. It is these local tailor made plans that will facilitate an appropriate response to the special situations and needs of all vulnerable groups as well as their full participation, within each particular community. It is important to engage people with disability themselves, their families and local DPOs in risk mapping so that they can determine possible barriers they may face in emergency situations. Similarly, participatory resource mapping will identify resources specifically available to people with disability such as accessible shelters, drinking water supplies and volunteers to provide physical support.

After the floods of 2004 in Bangladesh, Handicap International utilised transect walks, peer discussions, structured/non structured interviews and key resource people (occupational therapists and physiotherapists) to assess the immediate and long term needs of people with disability, defining the surrounding risks and available resources to meet them (HI 2005).

Other key recommendations involve the identification and registration of people with disability (along with their special needs) and the provision of both theoretical and practical training on disability issues for relief workers, community volunteers and family members. Involving people with disability and other vulnerable groups in the effective design and development of communication channels and early warning systems will ensure all community members are reached should a disaster be imminent.

In the aftermath of a disaster or emergency a number of key actions will assist the inclusion of people with disability within the immediate relief and rehabilitation measures that are launched. The rapid assessment forms and checklists utilised by humanitarian agencies should include questions on and raise issues concerning people with injuries and disability. The incorporation of local and international experts (psycho-social trauma counsellors, multi-disciplinary triage teams, disability

specialists, etc) will provide the necessary special focus within the rapid assessment and advisory teams that arrive soon after a disaster.

Plans for temporary shelters and camps, repairs and construction of latrines, water sources or housing should incorporate accessibility for people with disability as a key consideration. People with disability and other vulnerable groups are often more susceptible to physical, sexual and emotional abuse when staying in shelters or camps due to their reduced ability to protect themselves, hence their security and the minimisation of such risks is critical. It is also important to attend to the emotional and social needs of disaster victims to help them overcome normal trauma symptoms as well as provide professional assistance to those with severe traumatic distress, so as to avoid long-term psychological disabilities.

For the 'invisible' people with disability living in disaster-affected communities, especially those with intellectual and psychological disability, there may be a need to locate them and provide individual assistance as they may have difficulty understanding the realities of an emergency situation. Finally, with respect to responding relief agencies, it is necessary to develop effective coordination through cluster meetings of local and international NGOs, central and local government actors and disability-specific organisations.

In the rehabilitation and reconstruction phase, a focus on the participation and empowerment of all societal groups, especially those who are most vulnerable, will lead to a higher level of preparedness for the next emergency and an improvement of conditions that existed prior to the disaster. Unfortunately planners often recreate the inequitable status quo by failing to adapt the design of the re-built environment to meet the needs of people with disability. For example, if schools are not accessible for children with disability, this places lifelong limitations on them, affecting both their social inclusion and employment prospects.

The principle of *universal accessibility for all* should be paramount, ensuring appropriate 'design for all' features are employed when planning and reconstructing infrastructure or public facilities (see Whybrow, this issue). It is more cost effective to modify the plans for a new building at the outset than to adapt an existing structure retrospectively to make it accessible. While it depends on the type of building, adapting an existing structure retrospectively to make it accessible will cost an average of seven per cent of the cost of the total building. Whereas if you make it accessible from scratch, it will on average cost an additional one to three per cent of the total construction cost. The Indian Ocean tsunami has become a catalyst for agencies and planners to rethink their methods, putting issues such as universal design and accessible reconstruction much higher on the agenda of those who respond to emergencies.

Because of the vicious cycle linking disability with extreme poverty, it is also important to develop the self-help capacities of people with disability and their families through livelihood programmes (skills training, income-generating activities). After the 2007 Bangladesh flood, BPKS provided skills training on economic activities such as vegetable gardening, poultry and livestock management for over 12,000 people with disability and their families and petty shop management training for nearly 1,000.

During the rehabilitation stage, continuing medical care, rehabilitation and psycho-social support for persons injured or disabled by a disaster are also necessary, supporting their integration into long-term public health programmes. Establishing local community-based rehabilitation programmes is a further key step in ensuring all people with disability have access to community services and are treated as equal members of society.

Conclusion

Among the most vulnerable groups in emergency situations, people with disability are also among those *least* able to access emergency assistance and essential services. Where it comes to including people with disability within all the various stages of disaster response, there is a significant gap between existing policy mandates and the actual on-the-ground reality.

Humanitarian agencies and communities that take heed of the above recommendations and other emerging best practice guidelines in this area will contribute significantly towards bridging this chasm. This will require a coordinated, concerted,

collaborative and inclusive approach by organisations and civil society to address the challenges effectively. Such approaches also have the potential to stimulate the kinds of longer-term attitudinal and institutional shifts that will enable the rightful inclusion and full participation of people with disability within all social, educational, economic and political activities, which will ultimately result in a positive impact on poverty reduction.

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Note

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Implementing a physical accessibility project in Sri Lanka¹

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Some people are disabled not because of the effects of cerebral palsy, blindness, polio, heart disease, arthritis or age, but because of man-made features built into our everyday environment. They are the so-called 'architecturally disabled' (Goldsmith 1997). These features are planned into our home and community spaces, either deliberately or incidentally. They may be aesthetically pleasing, add glamour, save space, or are traditionally the way we build things, but they also serve to exclude a significant portion of the population from using them.

Awkward steps, tiny toilets, showers over a bath, poor lighting, uncovered manholes, street signs in the middle of a pathway, narrow doorways, and confusing signs constitute just some of these architectural barriers.

These man-made features can be difficult or hazardous to manage for many people in the community but impossible for people with disability thereby preventing them from accessing work, social, and educational opportunities (Goldsmith 1997; Jones and Reed 2005).

There are an estimated 480 million people with disability living in developing countries. Ensuring the physical accessibility of buildings and spaces is one way to assist in their empowerment and inclusion and is one of the principles of the United Nations Convention on the Rights of Persons with Disabilities. The United Nations considers it a 'reasonable accommodation' for organisations to remove architectural barriers in the process of their work (United Nations 2007).

The purpose of this paper is to explore the significant and resolvable problems of exclusionary building design. Using a case study of a project in Sri Lanka, it will highlight some of the challenges involved in creating more accessible buildings and spaces, and suggest ways development workers can get involved.

Access for All

'Access for All' (AfA) was a campaign that provided advice and advocacy to organisations involved in post-tsunami construction. It emerged from the rubble and ruins left by the tsunami that inundated the Sri Lankan coastline in December 2004. The idea was to create something positive from the destruction, a Sri Lanka that afforded the opportunity for everyone in the community to move around in as easily, as safely, and with as much dignity as possible. This meant consciously 'planning out' traditional barriers that had literally been 'built in' to the previously existing buildings and spaces.

AfA advocated universal design principles, that is, the notion that buildings and spaces should be safe, convenient, and enjoyable for use by everyone, including people with disability. This is different to 'setting aside' special places for people with disability and meant things like ensuring the main entrance to a building was accessible rather than allocating a special disabled entrance around the back or side (Goldsmith 1997).

Some of the 'built-in' barriers that had existed were obvious, but some were insidious and would not have been identified as such by the general observer or the people who had planned, designed, and built the places.

But, for 75 year old Wimal, who stooped low with an arthritic spine, hips, and knees, the 10 stairs at the entrance to a temple had become enough to bring to a halt a lifetime of dedicated religious and social ritual. His heavily pregnant granddaughter was also forced to stop going to the temple when she began to find the uneven, steep steps too difficult to negotiate, especially with no hand rail for support.

Forty-year-old Susantha, who had a law degree and was visually impaired, was not the only one who found walking to and from the bus stop to her workplace a major danger. Never mind the difficulties getting on and off the bus. The streets — with their uncovered manholes and drains, signposts that suddenly and erratically popped up in the middle of walkways, and rubbish dumped in various places by street vendors — were the source of many falls and stumbles. This included one incident involving a work colleague who drowned after falling down an uncovered manhole concealed by the rainy season's rising floodwaters.

The AfA campaign encountered some interesting challenges as the following case studies show.

An adaptable housing project

Two NGOs, one local (Navajeevena) and one international (Christian Blind Mission) conceived an adaptable housing project, constructing a village of around 50 houses to accommodate people of various ages and abilities. The partnership was called Navajeevena Development Alternatives (NDA).

NDA had extensive experience in disability work but had not participated in a construction project like this in Sri Lanka. They recruited an experienced accessibility advisor from AfA and a well known architect who was motivated to incorporate accessibility features into the houses.

Adaptable housing is not accessible housing. Not everyone needs a home with full accessibility features such as rails and special toilets. However, the idea is that the structure of the home should be easily adapted should a person ever lose their mobility (temporarily through illness or an accident, or permanently), develop a health condition that makes moving around a concern or difficult (for instance, pregnancy, asthma, heart conditions, continence issues), require a carer to assist them with their activities (including small children and the elderly), or simply experience some of the difficulties of growing old.

A key idea behind adaptable housing is that the home is built so that the access, layout, fittings, and spatial requirements of the home are suitable for a range of ages, abilities and mobility levels. It is not necessary, for instance, to make a 'special bathroom' for people with disability; it is only necessary to ensure the room is constructed in a way that makes it easy to adapt if necessary, and is something all family members can use.

With this in mind, NDA decided on key requirements for their houses. These included:

- appropriate width for all doors, corridors, and pathways leading to the house and around the community;
- minimum space requirements for rooms with special attention given to toilets/bathrooms, so that a mobility aid or helper can move freely inside if needed;
- provision for level access from roadside to building entrance and throughout the building;
- requirement for smooth surfaces and non-slip flooring; attached toilet/bathroom for easy access; heights and types of fixtures such as switches, taps and handles; and
- special attention to drainage in wet areas.

These features are all commonly specified in any housing and building plans, the NDA team simply ensured they met adaptability specifications.

In the adaptable bathroom, for example, NDA's main concerns were to provide specifically for level access, wide doorways, proper drainage, and adequate space for a wheelchair or helper to move around inside. If a particular person needed additional features at a later date, such as rails, a special chair to use over the squat toilet, or special tap fittings, then the design would allow for that.

In terms of access to the properties, many of which had to be built higher than ground level due to site conditions (built on a hillside), it was essential that space was made available to provide ramps as an alternative to steps if that should be needed (although NDA actually constructed both ramped and stepped entrances to most of the houses).

One of the main benefits of such an approach is that it is much more difficult and costly to modify a building once it is already constructed. This is true for all buildings, not just houses.

All NDA houses were to be built on essentially the same design (with some variation in layout). Like most groups involved in post-tsunami construction, the government assigned NDA land on which to build houses and a list of people who would be living in them. NDA was responsible for constructing the buildings on site, while the government was responsible for installing utilities connections such as electricity. Another donor came on board to construct roads around the site.

Standards

Standards provision was a significant issue. As private dwellings, houses do not need to meet stringent accessibility requirements, unlike public buildings in countries where there is legislation.

However, throughout Sri Lanka, post-tsunami houses were built en masse with most NGOs consulting with those who would be living in them and then providing their own designs to the people who, collectively, chose one or two of the designs they liked best. In cases like this, the houses could be considered 'public housing' and thus could potentially fall under regulation for construction of public buildings. In the absence of any legislation, however, NDA simply chose to incorporate adaptability.

It is common to use accessibility standards to construct accessible buildings. In Sri Lanka, United Nations Economic and Social Commission for Asia and the Pacific's accessibility guidelines (UNESCAP 1995) operated as the standards endorsed by government (not legislated) for design and construction of accessible buildings. They include some aspects relevant to housing. However, using the guidelines was problematic in this and other AFA projects, for several reasons.

Firstly, UNESCAP's guidelines did not address the fact that most people in Sri Lanka use a squat toilet, including most people with disability. A squat toilet can be made more accessible. There is no need to attempt to change a country's toilets to Western-style commodes, as recommended in the guidelines, as it may be undesirable from cultural, economic, and practical points of view.

There was a similar problem in the kitchens, which did not account for a rural Sri Lankan lifestyle.

Another major issue was that the standards relied on a model of a wheelchair that was not commonly used in Sri Lanka, nor were they based on Sri Lankan anthropometric data. Therefore it was uncertain whether the space requirements indicated in the guidelines would be suitable in this context.

And finally, building design in Sri Lanka often relies on the use of steps to avoid water from floods and heavy rains from

entering the premises. Steps are common at front entrances and within wet areas such as toilets and bathrooms. The design guidelines do not address any solutions to this apart from ramping, which could be inappropriate given limited space, and could instead be replaced by innovative drainage design.

Lifts are also suggested in the guidelines as a way to overcome the problem of steps. However, lifts are not feasible options for Sri Lankan rural households nor are they reasonable solutions for rural buildings such as schools, as many are struggling to find teachers and books let alone money to build and maintain lifts. It may also be inappropriate to build a long and expensive ramp. This does not mean the buildings cannot be used by people with disability. Instead, creative solutions needed to be devised to reasonably accommodate children, teachers, or parents with disability.

UNESCAP's guidelines were not intended to deal with special buildings such as schools or hospitals. In this setting, however, they were the only guidelines available and the problem was that these were exactly the sorts of buildings that were being constructed in great numbers.

With the question of relevance in mind, it was vital on this and other projects that someone with experience in the basic principles underlying accessible design was involved. In this way they could understand which guidelines might be inappropriate and work towards finding more appropriate solutions.

It is also worth noting that it is difficult to convince builders to implement standards (whatever their relevance) which are not legislated. This is particularly so when there is time pressure (such as in an emergency or relief operation), and if the builders do not really understand the importance of implementing the standards (an attitude we encountered frequently). What is more, the builders need to follow many other guidelines that are enforced (either by the government or organisational policies).

In such a context, donors and development organisations have a significant role to play by making it mandatory in their own organisational policies that all programmes and activities take place in accessible premises.

Experience and capacity

Even though NDA was committed to constructing an accessible environment — involving the donor, architect, engineer, site supervisors, contracted labour and everyone in between — there were many potential points of failure in getting designs implemented.

In the NDA project, the architect paid particular attention to ensuring the appropriate designs were laid out in detail and communicated the requirements to the rest of the construction team. However, on site, it became apparent that without adequate supervision, numerous mistakes would (and did) occur.

There were issues of 'we have always done it this way' as site supervisors and labourers dismissed or overlooked critical aspects of the accessible design during construction. Steps that had been eliminated in the plan were constructed, and lighting, taps, and power fixtures were fixed at the wrong heights.

The builders did not pay attention at times to specifics of the accessible design. The gradient for the ramp, the required gradient for the floor in the bathroom to ensure the water drained away properly (sometimes the floor sloped away from the drain), or where exactly to fix a tap were commonly overlooked. These are, in fact, vital elements of the design that can make the difference between a facility being 'accessible' or 'inaccessible', and if appropriate attention is not given to the details then accessibility goals will fail.

On another project, the on-site contractors found they could not position an accessible toilet where it was indicated on the architectural plan. They decided to relocate the toilet 100 metres away up a hill on a rocky, pot-holed pathway. The contractors clearly understood they had to build the accessible toilet — and even made a ramp to its entrance — but clearly did not understand the entire access issue.

On other projects, architects made designs they said were accessible, when, on review, they were not.

One of the key problems throughout was capacity: not enough skilled and experienced people to design and, importantly, supervise the process from conception to completion. It was very clear that every stage of the process needed close monitoring by a person experienced in accessible design.

Coordination

Even if someone strictly monitored the entire process and made builders correct their mistakes, accessible sites did not emerge without adequate coordination between agencies. The design and construction of the housing site involved numerous agencies. While NDA was in the process of constructing its houses and community centre, unannounced, the government positioned large electricity poles in places where they interrupted the accessible path of travel. Another was placed in the centre of a playground where it posed a safety hazard.

Meanwhile, while the donor that built the roads had been briefed on the accessibility considerations required on site, when it came time to build roads and paths to houses they failed to meet the design standards. In some cases, they even created several 30 centimeter high steps from roadside to property, making it difficult for any family member to access the property let alone a person with mobility impairment. It was clear that the work of all agencies needed to be coordinated and monitored better to achieve the design goal.

Communication with users

Communication was vital throughout the entire process and permeates each of the issues identified. But creating a community that is accessible for all also requires consultation with potential and existing building users, especially those with disability and their carers, who may not be using facilities due to the architectural barriers they face.

Throughout the AfA campaign, it was common to hear donors and construction teams comment that: 'only one per cent of people have a disability anyway, so why should we build this?' Such comments underscored a misunderstanding of the number of people with disability living in the community (estimates are at least 10 per cent), a misunderstanding about the basic premise of accessible design (it makes the community easier for all to move around in), and a misunderstanding about why they may not see very many people with disability on the streets and in public buildings (because they cannot use them).

In the NDA project, most community members had never heard about accessibility. Some were a little reluctant to agree to features such as a toilet attached to the house (though it remained outside and of squat design, but was relocated just outside the back door for easy access). However, after discussing the reasons, and then after experiencing the finished product, community members generally agreed the new design was much easier to use and had the added benefit of being close for night time use or if someone had an upset stomach. The elderly were particularly pleased because they no longer needed to walk over uneven ground in the dark to visit the toilet.

Conclusion

The challenges faced in accessible design in Sri Lanka are essentially no different from those encountered in wealthier countries. The main differences are the presence of legislation and a larger pool of people experienced in accessible design.

The challenges faced on this project are likely to be similar to those in other lower income countries. Development agencies all have a role to play in ensuring more accessible communities, firstly by ensuring the premises and spaces in which their activities, and activities of the groups they sponsor, are all accessible. This should be written into organisational policy.

Finding experienced, motivated, and creative professionals who understand the basic principles of accessible design is important, especially as they may need to deviate from basic design standards. Training may be necessary where there is none. Consulting with people with disability and organisations working with/for them is also vital.

Advocacy efforts to attune people to the needs and benefits of accessible design are required, as well as efforts to legislate and enforce accessibility guidelines. If this does not occur, people with disability must rely on the 'compassion' of willing building owners and design/construction professionals. Of course, it is easier to design an accessible building from scratch, but reasonable modifications to existing structures can also be made while paying attention to unique community contexts.

Building more accessible communities is not impossible and does not need to be more expensive. It does, however, require the commitment and coordination of creative and motivated people, which includes the commitment of development organisations to ensure all issues are addressed.

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Geodisability knowledge: Watching for Global North impositions

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Critical disability studies have shown that disability has been geographically and culturally defined and regulated by Western Governments. Thus, disability has history and context (Campbell 2008; Thomson 1997). This paper focuses on the impact these processes may have on people with disability in Sri Lanka.

An underlying dilemma presented here concerns the relationship between philosophy and action. A critique of the universalist approach to disability governance could occur through a critical appraisal of globalisation. However, some writers would argue that a focus on globalisation is a distraction from a more pressing concern; the continued Eurocentricism of knowledge and the domination of the Global North in social policy, law reform and research (Alatas 2006; Connell 2007). I argue that the United Nations delimits and denotes the kinds of bodies known as 'disabled' and this culture of knowledge production controls notions of difference.

Governmentality, geopolitics and geosurveillance

Foucault's early work (1977:195) on the panopticon gaze whereby 'inspection functions ceaselessly [and ...] the gaze is alert everywhere' is invoked in nodes of geodisability structures of systemisation and measurement. Though not reviewing extensive studies of panopticism, it is important to summarise its key features.

For Foucault, the panopticon became a motif and template for ordering socio-material realities. The panopticon 'is a diagram of a mechanism of power reduced to its ideal form ... it is in fact a figure of political technology that may and must be detached from any specific use' (ibid:205). The panopticon exposes the 'disability' as visible 'otherness'. Consequently, defining and socialising disability becomes about creating a physical/mental norm and where technologically not possible, a moral or social 'norm' that can be categorised, catalogued and thus regulated.

The rendering of kinds of humans is produced by space. For instance, the stranger crossing territorial borders without permission or correct papers becomes an 'illegal alien'. A more obtuse example is the French conceptualisation of disability as 'situation of disability' (*handicap de situation*). This idea bears witness to certain aspects of impairment that arise and then decline relationally and contextually (Winance, Ville and Ravaud 2007).

The institutional strategic gaze situated in the UN is able to examine, normalise and condition nation states. International disability norm standard setting is represented as a system formulated by consensus, is transcultural and objective. Knowledge formation by international consensus is not a level playing field. Connell (2007) argues non-Western approaches are not taken seriously enough to rupture the colonial experience.

An alternate reading is to see geodisability knowledge as naturalising dominant ways of seeing (knowing), citing (summoning and hailing) and situating (localising) disability. Of course increased geosurveillance can be associated with global concerns about risk and dangerousness. The enemy can be transfigured from the commonly known 'unruly potential terrorist' to another kind; (those sick and/or disabled) who are represented as a global, ethical and economic burden, contributing to nationalist 'degeneration'.

Governing from a distance operates through two discursive modalities. The first is *denotative* — a cartographical description of a particular spatial zone (our interest is in the mapping of zones of 'health' and 'not-health'). The second, founded on the denotative, forms an *authoritative atonement*, a discursive canon (such as international disability norms) which constructs foundational and thus sayable 'statements' (for example, 'who' is legally a 'disabled person') guiding policy formulation.

The impact of *authoritative atonements* on the Global South can be even more devastating given the tendency of the colonised to have a 'captive mind' — '... the inability to be creative and raise original problems, the inability to devise original analytical methods, and alienation from the main issues of indigenous culture' (Alatas 1974, cited in Alatas 2006:47).

The erasures of 'place' and localised particularities have been the foundation of Western philosophy and thought. Consequently space 'had to be dissociated from the bodies that occupy it and from the particularities that these bodies lent to the places they inhabit' (Escobar 2001:143). Enacting universalised geodisability knowledge production is a major modality for governing disability, placing disability out of space, or in outer space, despite the implicit materiality of the creation and living of impairment.

The *outer* space often has a similar aesthetic irrespective of geography — for example, all hospital and care homes look alike — in other words they could be any *place*, any where. The invention of disability occurs in the local and embodied notion

of 'place', in distinctions made between health, not-health, disability, demonisation and so on. The stories of disability and the handling of anomaly are grounded in the local (village) contemporaneity, and based on Eurocentric notions derived from colonial ideologies.

Intercourses of colonialism: *Rattling the can*

Law's (1999) study of the management of Portuguese imperialism identified three key technologies necessary to govern, namely, *documents* (policies and regulations), *devices* (technologies of things, instruments and resources) and *drilled people* (the docile civil servant or administrator who knows what and how to do it, and performs the task).

By shifting our gaze towards the ways Western eyes represent non-Western others, this new way of *seeing* prompts questions such as: 'what is development? Who says that is what it is? Who aims to direct it and for whom?' These questions can be solicited from key policy and legislative documents which act as *sites of enunciation*. It is possible then, to ask:

- Who are the agents of knowledge (international bodies, overseas universities, INGOs/NGOs, DPOs, local governments, indigenous universities)?
- How do they conceptualise disability and health; where are the analytical silences?
- Who is being empowered and who is being marginalised?
- What are the implications of states (and individuals) rejecting the trend towards adopting UN norms?

Non-Western countries are perceived as deficient or in a state of arrested development. Countries like Sri Lanka are viewed *ontologically as disabled*, therefore in need of rehabilitation and ethical guidance. Global South countries have cultural approaches to disability that are viewed as bereft, with no original research contributions to global knowledges and have schemas of disability with arcane approaches to service delivery.

Contrary to the view that globalisation increases access to knowledge it can by default, induce a sense of *ignorance* (that is, of what we know we do not know, and what we do not have in terms of resources and technologies) on the part of the Global South. This ignorance effect is not mutually shared by the Global North and South as it can be argued that the Global North often assumes they don't need to know about the Global South.

Hellinger (1987) warned of the danger that increasing overseas aid would have on civic values and diversification of human services practices. NGOs are conceptually grounded in a charity ethos inhibiting the development of a realigned focus

that promotes citizenship and rights-based social movements. The 'reprivilidging' of indigenous responses to social concerns remains difficult as the locus of power is still retained by externally funded NGOs.

Transnational actors/networks are made up of a composite of ideas, resources and activities circulating through a range of fora playing an active part in encouraging states to embrace international norms, not just through the usual channels of political and economic persuasion, but through domestic socialisation. Regulation and prescriptiveness at an international level produces a homogenisation in reforms. The place of 'home grown' indigenous distinctiveness in terms of needs, processes and service delivery outcomes appears ambivalent or at best uncertain.

Agreement with dominant agendas is more probable if exposure to alternative conceptual and planning frameworks is absent. A question emerges: where do sociologists, policy makers and researchers access counter theories, methodologies and scholarship *developed independently* of aid agencies and overseas stakeholders? Investment in a particular social and economic sector by many NGOs and multilateral financial institutions means the site of interest convergence occurs in the developmental activities of donor agencies and overseas-funded research centres that, by default, create parallel institutions potentially weakening the capacity and 'responsibility' of the state and academy.

The Sri Lankan Government experiences increased pressure from the UN and international financial donors to conform to the universal project of disability standards, definitions of disablement and externally imposed models of service delivery, legal and policy frameworks. Concepts such as 'health' and its opposition, 'disability' are assumed to have universal and unchanging import, erasing much of the different and contrary terrains to which these concepts might apply. Interest convergence can then result in the imposition of fixed prescriptive disability *definitions* developed externally and imposed upon aid practices. A decolonised project therefore needs to highlight the importance of both conceptual and praxiological distinctiveness.

Imported responses: Geodisability knowledge

In the West, until recently, the dominant paradigm for understanding disability has been the 'medical model' where disability is assumed to have an existence altogether autonomous from any social context. The pre-eminent apparatus controlling the delimitation of disability originates with the UN. Consensual international disability norms makes possible the disclosure and visibility of disability dynamics at a country level and for the World Health Organization (WHO) to map disability globally.

A number of salient definitional instruments exist and are mandated for use by UN member nations, of which Sri Lanka is one, for the purposes of enumeration and programme development. The Human Development Index, a comparative measure of poverty, life expectancy and education, has been used by the United Nations Development Programme since 1993 as a tool to apportion funds. Sri Lanka is ranked 99 and has a medium human development ranking. UN formations of disability are deeply embedded with a broader classification of disease, which delimits disability in relation to a so-called 'objective' comparator referred to as health status (a person without a health condition). This is an instance of colonial enframing where partitioning of 'disability' and 'not-disability' obscures cultural differences.

Classifying disability

In January 2001 the 54th World Health Assembly adopted the International Classification of Functioning, Disability and Health (ICF). The new system inaugurated four dimensions related to disability: impairment, activity, participation and context. Its authors argue that the aim of the ICF was to develop a common language for speaking of 'health' and by default 'disability'. Moreover, the new ICF provides the tool to implement various UN instruments and enact coherent national legislation. Without the ICF, the networked nodes of UN governance would have difficulty border crossing. Advocates of global geodisability templates argue that universal systems can be used to bring 'into line' renegade nation states that do not appropriately plan for the needs of people with disability.

The WHO disability framework is premised on disability being objectively and universally known, mapped and treated. Furthermore, the new ICF formulation while cognisant of the 'participatory' and 'contextual' dimensions of 'disability,' continues to be constitutionally aligned with and thus becomes a sub-directory of the International Classification of Diseases ICD-10. This narrow framing within a disease paradigm will most likely ensure that etiological factors remain pre-eminent and the social context eclipsed.

In Sri Lanka the usage of the comparator of a person without a health condition can obscure rather than clarify service delivery needs, especially if deliberations do not factor in socio-economic considerations, access to resources and consequential social exclusion. Mental health is described by WHO (2006) along the lines of coping with the normal stresses of life. But as Fernandopulle et al (2002) points out, the notion of normalcy explodes given the almost normalised extra stress of living with inter-ethnic conflict and war.

Different cultural locations within the country would have a different threshold as to what counts as disabled or not: for example, children without birth certificates and with cognitive

impairment may have no real sense of actual age, hence communities have no real sense of developmental milestones or delay, therefore individuals are not seen as impaired. A more recent tool of governance is the 2006 Convention on the Rights of Persons with Disabilities (CRPD). The Convention's strength is its formulation of disability that transcends functional and medical orientations of traditional disability models. The Preamble at [e] states (UN nd):

disability is an *evolving concept* and that disability results 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 (emphasis added).

Article 1 of the Convention lists the more usual type of functional and classificatory approaches to disability, yet there is room to even interpret these categories through the lens of an intercultural understanding as made possible through the emphasis of the Convention's Preamble. The impact on Sri Lankan disability affairs is uncertain. Possibly the Convention will stimulate debate and change around disability or alternatively impose little understood legal standards and obligations.

However, the issue of UN norm standard setting is deeply problematical; so little research exists to examine the processes of developing these standards and the role of cultural norms. The work of Lord (2004) documents the tensions and deals made between NGOs regarding access to planning forums and exposes the less known fact that internationally, only seven organisations have UN Economic and Social Council status, each based in the developed world with limited regional representation.

What we can conclude is that even before exploring disability policy in the Sri Lankan context, the international system of knowledge articulation is highly regulated and prescriptive. Europeanised regulatory regimes often resulting in non-Western countries with few resources feeling somewhat overwhelmed by the pressure to conform to (alien) global rules.

Sri Lankan disability scenes

Sri Lanka lies on the far southern edge of the Indian sub-continent. It has a population of around 20.9 million and is a country that has been in the grip of a terrorist crisis for 25 years, resulting in large portions of the Government budget being spent on defence and a high prevalence of war-induced physical, cognitive and psychological disablement.

The contemporary situation of people with impairments in Sri Lanka is essentially a biopolitical question. The counting of disabled Sri Lankans is a vexed question. Social planning is made difficult by a shortage of information about the scope

and needs of Sri Lanka's disabled constituency. In Sri Lanka, disability is mainly produced through war, natural disasters, ageing populations and large numbers of people undertaking high-risk work.

Despite challenges, a specific Sri Lankan pattern of impairment can be described: there is an estimated population of 900,000 people with disability (Wijewardene and Spohr 2000). Although the incidence of physical disability produced by war has not been enumerated, the Asian Development Bank estimates (2005) are in the vicinity of 100,000 persons. The high levels of mental illness indicates the requirement for a far reaching approach to mental health taking into account the consequences of living with years of civil and military conflict.

The suicide rate ranks seventh in global statistics, with a ratio of 31:100,000. Deaths due to suicide are estimated to be 106,000, twice the number due to war (WHO 2006). The 25-year war has produced significant levels of disablement of between 10,000-15,000 soldiers (Wickramasinghe 2006). It is uncertain what impact such high levels of disability have had on transforming attitudes towards bodily or mental differences by non-disabled members of the community.

With the exception of work by Urugoda (1977, 1987, 2008) on health systems, Obeysekere (1969, 1976) on indigenous psychiatry and Silva (1991, 1994, 1997) on the sociology of colonial epidemics, there is almost no contemporary cultural and historical research on disability in Sri Lanka. Existing research has been dominated by medico-clinical studies of mental health issues around suicide, rehabilitation of soldiers with disability, agency projects and children with communication disorders. Inputs from medical anthropology, political science, sociology, Sinhala/Tamil linguistics and women's studies have been glaringly absent. A characteristic of research is the adoption of Western approaches to research methodology and the transmission of Western modalities to interpret indigenous situations.

The major impetus for law and policy reform has been from forces external to the country and to a lesser extent, advocacy from the local disability rights movement. Policy development and legal reforms related to disability have been slow. In 1996 the Sri Lankan Parliament passed three significant pieces of legislation: the Human Rights Commission Act (No.21 of 1996), the Protection of the Rights of Persons with Disabilities (No.28 of 1996) and the Social Security Board Act (No.17 of 1996). These changes in the legal framework are part of the country's ongoing alignment with the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993).

Most disability legislation, however, lacks specific mechanisms for the implementation and enforcement of the rights ascribed in the legislations, especially a process for the bringing of individual or group complaints. In 2003, the Sri Lankan

Government introduced The National Policy for Disability, a social framework to accompany the 1996 legislation. Increased international communication has facilitated the development of a Sri Lankan disability rights movement led by and for people with disability. Still, the dominant image of Sri Lanka is of a small island crowded in by a cacophony of NGOs, externally-based donors operating within neo-colonial nodes and a web of internationalised regulation.

Indigenising disability studies and research

For critical disability studies to grow within Sri Lanka, a vibrant training, research infrastructure and agenda is needed. Greater challenges exist at the institutional level beyond the specificity of teaching and researching disability studies. Sri Lankan social science scholars experience a restricted flow of information, resources and exposure to international debates. The degradation of the teaching and research enterprise is heightened by the peripheral role that Sri Lankan universities and 'native scholars' [sic] command from the broader academic community, NGOs and overseas funding bodies.

Accentuating these concerns is the conundrum where home-grown scholars still look to the West as the 'gold standard', and are required to engage in Western knowledge-talk in order to be heard (Chakrabarty 2000). A primary task then is to broadcast the parochialism of health and welfare scholarship. There is a need to promote indigenised scholarship that builds up epistemologies and service practices. Where there is overseas funding, programme and course development, it is guided by off-shore accreditation principles and institutions. A vacuum exists of non-clinical social science, disability studies-orientated research conducted by both universities and peak NGOs.

The first challenge is to engage in education for capacity building, and for the disability rights movement to negotiate complex debates over concepts of diverse disability formations. This is not unreasonable given the rich multivariate cultures within Sri Lanka and the range of experiences with colonialism. In contrast to homogenising global discourses of disability norms and practice, localised politics and tensions infuse translocal discourses of disability, illness and health. Global South scholars, already working at the periphery of the Western academy are accustomed to negotiating (Western) theory across space in a profoundly different place.

This process of 'translation', the notion that Sri Lankan history and cultures contain 'original possibilities', should act as a beacon illuminating the darkness of postcolonial uncertainties and unknown futures. Legal developments cannot be effective in terms of emancipation until education for justice occurs with teachers, practitioners, people with disability and human services personnel. Only limited training and development

activities have addressed recent shifts in the reconceptualisation of disablement and the public law interest implications with legal mobilisation and reform agencies. While legislative reforms create legal interests, statutes do not create institutional resources to activate those rights.

We know that Sri Lankans with disability have limited knowledge about the existence of services and law. Although recent disability legal and social policy reforms suggest an adoption of a liberal rights framework, this shift needs to be reflected in training and pedagogical strategies to negotiate existing service provision structures and attitudinal responses in fields still informed by the notion of disability as tragedy requiring charity and asylum.

Without a critical appraisal of liberal rights and Eurocentric frameworks, there is a danger of entrenching an unquestioning conformity to externally imposed regulatory standards, leading to a reliance on the 'expertise' of foreign advisers who may have 'different' interests in Sri Lanka, whilst diminishing the wisdom of Sri Lankan perspectives. It is imperative that critical disability studies education be embedded within the Sri Lankan environment. Instead of putting money primarily into supporting NGOs, overseas donors and universities need to be encouraged to develop partnerships with Sri Lankan universities through cooperative curriculum development, publications assistance, scholarly exchanges and research funding.

Conclusion

This paper attempts to make connections between the development and advancement of disability conceptualisations and service delivery models, and the continued impact of neo-colonial governance. What becomes clear is that capacity building pedagogy is fundamental to resisting the imposition of culturally eugenicist norms in the form of international disability norm standard setting that may result in the disappearance of particular Sri Lankan formations of disablement. The CRPD may facilitate debate around cultural approaches to impairment and difference. Yet there are no certainties.

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Toward decent work for people with disability: ILO global perspectives and regional examples

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Introduction: The global perspective

Unique among UN agencies for its tripartite structure of government, trade unions and employers' representatives and its exclusive emphasis on the world of work, the International Labour Organization's (ILO) purpose is to promote decent work for women and men everywhere, including those with disability. The ILO defines decent work as productive work in conditions of freedom, equity, security and human dignity.

People with disability, regardless of where they live, want and need the same things as everyone else — a home, good health, and a full life, including the chance for decent work and the resulting financial, social and psychological benefits. Many people with disability have proven themselves in formal and informal workplaces and as operators of small and large businesses. However, the large majority of people with disability face significant barriers to accessing decent work and the experiences and skills development opportunities that make decent work more likely.

Comprehensive international data and comparable national data related to disability are lacking but people with disability are not an insignificant group. Ten per cent of the world's population or 650 million people have disability according to World Health Organization (WHO) estimates, and 470 million of them are of working age. More than half reside in Asia and the Pacific.

In developed countries the incidence figures can be even higher than the WHO estimates while developing countries figures can be significantly lower due to under-reporting of disability, lack of rigorous statistical analyses or factors. For example, Indonesia and Malaysia report only a one per cent disability rate (UNESCAP 2006).

Workforce participation

The overall workforce participation and employment rates of people with disability are significantly lower than those of non-disabled people, and women with disability face even greater barriers. In EU countries, women with disability participate in the labour force at a rate of 49 per cent and men with disability at 61 per cent as compared to their non-disabled peers who participate at rates of 64 per cent (women) and 89 per cent (men) (Eurostat 2002). When people with disability do work they are more likely to have smaller incomes, especially women with disability. Figures from the United States show that the

median annual earnings of people with disability who work full time are US\$34,200 as compared to US\$40,700 for their non-disabled counterparts (Erickson and Lee 2008).

Education is crucial to future participation in training, employment or self-employment. Yet, it is estimated that one in three of the world's 77 million children who do not attend school regularly have disabilities (World Vision International 2007). UNESCO (2006) estimates that only 10 per cent of children with disability attend school in developing countries.

Figures to illustrate the disproportionate representation of people with disability in vocational training and higher education are difficult to come by. But, in 2000, Australia found that 11.8 per cent of the total working age population had enrolled in its training and formal education system, compared to only 3.3 per cent of working age people with disability (ILO 2006). Reports from Asian and Pacific developing country representatives at ILO meetings suggest that only about three per cent of people with disability have benefited from vocational training.

Considering these figures, it is not surprising that people with disability are among the poorest of the poor. The UN estimates that in developing countries, 80 per cent of people with disability live in poverty and of these, around 80 per cent live in rural areas. This poses particular challenges to accessing training and work opportunities. Many people with disability work in precarious employment, have established microenterprises or started income-generating activities in the informal economy or the agricultural sector since these may be the most realistic options for earning money and contributing to family livelihoods. These options often require access to business development services and credit.

Credit access is a particular barrier faced by people with disability, especially the most poor, least educated or those who face transport barriers. This lack of access has been documented in ILO technical cooperation projects and by NGOs such as Handicap International (see HI 2006).

These figures tell a story that is well known among people with disability and those who serve or advocate for them. Whether people with disability live in the most industrialised countries of the world or in the least developed, they face similar patterns of reduced socio-economic participation and the same barriers to work. In the United States, people with disability cite discrimination and transportation as the major reasons for

not being employed (NOD 2000). These same issues prevent people with disability from accessing credit in Africa, or securing services to increase their employability in Cambodia.

The economic cost of disability

From a global economic perspective, the cost of disability exclusion is great. A World Bank commissioned study found it to be between US\$1.37 and US\$1.94 trillion, or an average annual global GDP loss per people with disability of US\$2,486 to \$8,226 (Metts 2000). In OECD countries (OECD 2008) the cost of disability benefits alone is 1.23 per cent of overall GDP.

People with disability who are not working represent an under-utilised human resource. Increasingly, companies are realising the business case benefits for hiring people with disability such as their productivity, excellent attendance, and a resulting increase in overall employee morale and team work when people with disability join the workforce. Corporate social responsibility and basic diversity principles that suggest the customer base should be reflected in the company's workforce are additional features of the business case. Numerous company examples, many with specific data, support the business case (Perry 2007; Suter et al 2007). The public image factor was recently given strength by a US-based survey which found that 92 per cent of respondents were more positive about a company that hired people with disability and 87 per cent were more likely to give their business to such companies (Siperstein et al 2006).

It is clear that when included, people with disability contribute to the economic development of their countries, as employees, entrepreneurs and consumers. Too often, however, they are excluded from the very activities, such as education and training, and denied access to services such as transport, which provide a path to decent work. The barriers have been well documented elsewhere and include those which are *physical*, such as training centres and workplaces which are inaccessible; *information and communication* related, such as training approaches which fail to take into account the needs of people with disability; *legal or institutional* such as a lack of appropriate laws or policies to address rights or the failure to implement them when they do exist; and *attitudinal or discriminatory* barriers which can range from an overall disregard to issues of disability to fear or ignorance.

The ILO and its means of action

As a social justice organisation, the ILO is committed to promoting equal rights and equal opportunities for women and men with disability to obtain decent and productive work. The ILO has three means of action toward reaching its goals and objectives: knowledge development, advocacy and technical cooperation.

Knowledge development

The ILO is involved in a variety of knowledge development and sharing activities that are most often captured in publications and research documents that promote a rights-based approach, foster inclusion, address the social partners or document lessons learned from technical cooperation activities. The ILO's recent publications concerning the training and employment of people with disability are widely available in hard copy and through the ILO websites (www.ilo.org/employment/disability and www.ilo.org/abilityasia) as well as through the InfoBase of the Global Applied Disability Research and Information Network on Employment and Training — www.gladnet.org.

Advocacy

The ILO has a long history of promoting equal training and employment opportunities for women and men workers with disability through its standards, all of which apply to people with disability, although some particularly single out their needs and rights. As early as 1925, the Workmen's Compensation (Minimum Scale) Recommendation 1925, (No.22) included provisions for vocational rehabilitation of workers with disability.

The concept of vocational rehabilitation and inclusion was advanced with the Vocational Rehabilitation (Disabled) Recommendation 1955, (No.99). It pioneered the inclusive approach in relation to vocational training and promoted the need for rehabilitation, equality of opportunity and equal pay a long time before disability rights was on the global agenda.

These early standards were followed by the Vocational Rehabilitation and Employment (Disabled Persons) Convention 1983, (No.159) and its accompanying Recommendation (No.169), which promote the principle of equal treatment and equal opportunity between workers with disability and workers generally, as well as equal opportunities between women and men with disability, recognition of the need to address those living in rural areas, and the acceptance of special measures such as affirmative action. Convention No.159 continues to be ratified and relevant today, more than 25 years after its adoption and has been given renewed attention as a result of regional Decades of Disabled Persons and with coming into force of the UN Convention on the Rights of Persons with Disabilities (CRPD).

In 2002, the ILO adopted 'Managing Disability in the Workplace', a code of practice that builds on the principles of equal treatment and equal opportunities for people with disability in the workplace. Primarily a practical guide for employers, the code also outlines roles for workers' and employers' organisations and competent authorities in assuring the active and equitable participation of people with disability in employment.

Technical cooperation

While the ILO is involved in a variety of policy, advocacy, knowledge development, and technical cooperative initiatives in the Asia and Pacific region that have relevance to people with disability, the following case study illustrates practical approaches to addressing disability and disadvantage in the region.

An example of ILO activities is provided in the following Cambodian case study.

The APPT project in Cambodia

Cambodia is recovering from years of civil unrest. While the economy is now developing rapidly, the situation in more remote and rural areas remains especially challenging for people with disability. The APPT project was started in 2002 and ended in 2007, although the work has been sustained by several other organisations.

The project grew out of another ILO project that used trained field workers to find people with disability and work with provincial training centres (PVCs) to foster the inclusion of trainees with disability in the PVCs. Many people with disability benefited, but others who wanted training could not because they were unable or unwilling to travel and meet the time commitment of PVC courses, did not meet literacy or other requirements, or their sheer numbers could not be accommodated.

A methodology called Success Case Replication (SCR) was field tested among people with disability as an alternative. Initial results were promising and the ILO initiated the new APPT project primarily based on the SCR approach.¹ Basically, SCR, or peer training, calls for village-based microenterprise owners or operators of successful income-generating activities to train people with disability in the business and technical aspects of the microenterprise.

The project was implemented in three provinces (Siem Reap, Kompong Thom and Pursat) and had a coordination office in Phnom Penh. It was designed to provide skills training, business start-up support, including credit or grants, and follow-up assistance.

The project used the following steps:

- locate successful village-based entrepreneurs;
- evaluate the financial viability of their businesses (eg, net return, market capacity, etc);
- assess entrepreneur's willingness to train and the market's ability to sustain a similar business;
- screen and select trainees;
- match trainer and trainee(s);
- establish a practical hands-on training programme;
- supervise and monitor the training and provide supports, including allowances, as needed;
- plan the business with the trainee (before and

during training);

- arrange for access to credit;
- provide follow-up and business development support; and
- achieve secondary replication of the first level success (that is, trainees who successfully start businesses become trainers).

In addition to SCR, the APPT project placed individuals in other vocational training, such as other NGO training programmes, when this was in the best interest of the project clients. However, SCR was the primary training tool. The project operated a participant fund used to pay training fees for trainers, special allowances for those in training to cover costs related to equipment, accommodations, transportation, etc, and grants for business start-ups and business enhancement. When more than US\$50 was needed to start-up or develop businesses, small loans were offered. However, the use of loans declined in the final years of the project. Accessing credit outside the project was difficult, however, because the participants often lack collateral, had difficulty accessing the microfinance institutions or met with other obstacles.

Case studies

The project helps people like Tok Vanna, a 32-year-old man and father of two who lost both of his lower arms as a result of a landmine accident in 1990. A former beggar, Vanna is now a vendor who, instead of asking tourists for money, sells books and souvenirs to them in Siem Reap, site of Cambodia's famous Angkor Wat temples. The APPT linked him to another book vendor (also a man with disability) who taught Vanna how to get started in and manage the business. The project provided him with a loan so he could buy his cart and sent him to school to learn English so he could communicate with the tourists. He got money from another source for initial supply of books and products. Vanna now earns US\$65 per month (a good income for Cambodia) and is able to support himself and his family.

It also assisted Mey Nith, a single 35-year-old woman who lives with and cares for her 58-year-old mother in the remote Touel Village, 45 km from Siem Reap town. The field worker learned about her from other villagers in 2004. Blind in one eye from an accident, she stayed at home and did not have any source of direct income. Nith cannot read or write but took to the idea of operating a business as an ice pop vender. She was trained by a woman in the neighbouring village who provided her with the skills to make the ice pops and the information she needed to get started in business. Training only took one week and the trainer did not charge a fee. The APPT project provided a grant of \$US25 so she could buy initial materials and set up a small storefront.

In the two and a half years since she started her business,

APPT staff have made eight follow-up visits and during that time, Nith has maintained and expanded her business. Although she has never been to school, she fully understands the calculation of her net profit! She makes \$US1.20 per day according to analysis of her costs and income by project staff, or about \$US35 per month. She also now sells goods such as sugar and cigarettes along with her ice pops, which increases her monthly income to about \$US50. She has also started to buy and raise pigs for sale and purchases gold as an investment.

She supports her mother and has improved her home with the money she earns. She is able to eat more nutritious food and buy medicine when she or her mother needs it. Nith is willing to train others but, as a savvy businesswoman, she refuses to train anyone in her village. She does not want the competition.

Although the focus of the APPT project was to serve people with no skills or business, the participant fund allocations for training-related costs, grants and loans, were also used for upgrading people with disability's existing businesses in cases where no training was needed.

The ILO executed the APPT project in collaboration with the Ministry of Social Affairs, Veterans and Youth Rehabilitation (MoSVY), its provincial offices and collaborating NGOs located in the project sites. Local NGOs helped to administer the participant fund. Seconded government staff was the main source of human resources, serving as field workers. They were critical to the success of the project, since they had to identify trainer and trainees, supervise training and provide business development support as well as access other community-based services that might be needed.

Impact of the APPT project

As a result of the project, 958 people with disability were served over a five-year period, with more than half being female. Seventy-seven per cent started microenterprises or enhanced their businesses; 56 per cent of those who succeeded were female. During the last two years of the project, 93 per cent of those served were found to maintain their business one year after start-up. As the project staff developed their expertise and the system become more efficient and effective, the success rate improved.

The average income of participants before participation in the project was \$US6 and after it was \$US32. (The poverty rate in Cambodia is \$US25 per month). Families are usually engaged in a variety of income-generating activities, so the contribution of the person with disability served by the project was often only part the total family income.

Many of the income-generating activities that formed the basis of the microenterprises fed into the rural economy; occupations such as pig raising, making rope tethers, or crafting cement jars for storing rain water. Others involved simple food

processing and sales such as producing soy milk, sprouting beans, making ice cream or producing Khmer cakes or noodles. In Siem Reap, where the tourist industry increased rapidly during the life of the project, stone carving, basket weaving, making a variety of souvenirs, and selling books to the tourists proved productive and profitable.

Besides the increase in income, people with disability reported an increase in their participation in social and community activity, greater self-esteem and feeling that they are more respected by their community members and neighbours. A needs assessment of women as compared to men during the project indicated that women have a greater need for skills training than men, and are more limited by mobility and social isolation. The aspects of the programme that brought training to women, within their home, village or nearby community was most welcome and their social engagement was found to increase considerably as a result of their microbusinesses. It should also be noted that many of the trainers were people with disability and that many people agreed to train others once their business was up and running. A key task of field workers was to ensure that business replication could be sustained by the market.

The significance of the project in working with people who lacked literacy skills, communication skills, had never worked before or who had severe disabilities should not be overlooked. For example, Hang Hatch, a 52-year-old man who lived in a remote area, attended school to grade 8 had never worked before an APPT field worker found him with the help of the local village chief. He learned to make ropes for the animals which his sons sold to a middle man. Hang Hatch described himself as being reborn and was finally able to contribute for the first time to his family income. Several young deaf women who lacked communication skills were able to learn skills like soy milk production and ice cream making and sold their goods at local schools and villages.

In many respects the project did not result in what the ILO would call decent work. However, it did respond to the need for poverty alleviation and a government request to address issues of severe rural poverty and lack of work opportunities. For many, they will start on the path to decent work. Simultaneously, the ILO in collaboration with the government, sponsored regular rights-based training to promote ILO C 159, the then upcoming CRPD and human rights of people with disability as guaranteed in the Cambodian Constitution. A draft law to protect the rights of people with disability is now working its way through the Cambodian Parliament and the SCR approach has made its way into at least two policy documents (MoSVY Strategy Plan and the Victim Assistance Plan for Landmine Survivors). Several international NGOs (eg, World Rehabilitation Fund and HelpAge) and

national organisations (eg, MODE and the Buddhist Fund) have adopted the peer training approach and are using tools developed by the project. The tools are available in Khmer and English and include:

- 'Replicating success: A manual for programme operators' (currently in draft; the final manual is forthcoming);
- 'Managing for Success': A database, evaluation and impact assessment system including a CD Rom and instruction manual;
- 'Training for Success': A manual for peer trainers on providing one-to-one peer training for people with differing disabilities; and
- 'Replicating Success': The video.

Summary

People with disability face barriers to skills training and employment regardless of where they live. The interventions to mitigate these barriers should always be based on principles of rights, dignity and equal employment and equal opportunity. However, the nature of the interventions may vary depending on the resources and strengths of the country or the community as well as the training needs of the people with disability and the opportunities in the market. This case study shows the importance of market-driven training for successful employment.

In the case of Cambodia, people with disability seemed more severely limited by their lack of education and the overall poverty and underdevelopment of their communities than by disability issues, which no doubt further marginalised them.

This example illustrates creative approaches to implement rights and promote opportunities and address the barriers faced by people with disability. People with disability were directly involved in the design and implementation of activities. The project was operated with an advisory group inclusive of major stakeholders, including disabled people's organisations. Needs assessment and the final evaluation included the voice of people with disability directly.

Note

1. See ESCAP, *Cost-Effective Employment Promotion for the Rural Poor*, New York, 2000 and ESCAP/FAO, *Success Case Replication*, Bangkok, July 2000.

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Voices for change: Advocacy for changing culture and policy for women with disability

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The Australian context

World wide, women with disability are among the poorest and the most marginalised. They are affected by both disability and gender discrimination, which in combination excludes them from society and drastically reduces their life choices.

In Australia, women continue to struggle to overcome the affects of gender bias. Australia is not alone in manifesting this bias — it has a negative affect on women from the majority of cultures around the world. Years of affirmative action, which started in Australia between 1972-1975, did not achieve gender equity. Retrograde steps over the past decade have meant that women in Australia continue to have lower levels of employment, and be embarrassingly under-represented in executive positions and on company boards.

There is an increased concentration of women in low paid, part time, casual employment, and in 2008 there was a difference of 35 per cent between men and women's average weekly earnings (EOWA 2008).

Levels of violence against women, both in the domestic and public sphere, are high, despite numerous public campaigns. These include 2004's 'Partnerships Against Domestic Violence' and the 2006-07 'Violence Against Women: Australia says NO' campaign, along with a number of domestic and family violence and sexual assault initiatives, and UNIFEM's annual White Ribbon Day campaigns.

A 2005 personal safety survey (Australian Bureau of Statistics 2005) found around one in five Australian women have experienced sexual violence at some stage in their lives since the age of 15 and one in three experienced physical violence at some stage in their lives from the same age.

Australian women with disability

It is within this cultural context that we must view the status of Australian women with disability. Available research on levels of violence experienced by women with disability consists of either anecdotal evidence or small, isolated research projects (see, for instance, Davidson and McNamara 1999; Keilty and Connolly 2001; Cockram 2003 in WWDA 2007b). These suggest the incidence of violence against Australian women with disability is anything from two to 10 times that experienced by non-disabled women.

One in five Australian women has a disability or disabilities, and yet Government policy in Australia, irrespective of political

persuasion, has largely ignored this group (ABS 2004). Thus, their development needs are parallel to women with disability in the region's developing countries.

Historically, the education available to women with disability in Australia has been extremely limited. Currently, although women with disability attain nominally better levels of education than their male counterparts, they are over-represented in stereotypical workplaces. The very nature of their qualifications reduces their employment choices to those areas where non-disabled women are experiencing the worst pay conditions and outcomes. Negative employer attitudes further relegate them to the lowest of the low paid, in part-time, casual, insecure jobs. For those not employed, Government pensions are grossly inadequate. Those new to job searching subsist on a punitive allowance which is far lower than the Disability Support Pension.

Gender-targeted systemic advocacy from national peak disabled people's organisations (DPOs) has been non-existent. The bulk of systemic advocacy drawing attention to the low status of women with disability has been carried out by Women with Disabilities Australia (WWDA), the country's only national cross-disability women's NGO. At present, WWDA is the only Australian DPO espousing feminist, disability, and human rights' philosophies. It operates as a collective of women with disability to address issues which affect their peers.

In Australia, the culture of exclusion of women with disability which permeates society also exists within the disability movement. Although now autonomously managed by people with disability, the DPOs originated from a medical model of disability, resulting in peak organisations representing diagnostic groupings. The perspective of women is overlooked. In cross-disability DPOs, women have been relegated to support roles and their specific issues ignored. Similarly, in the women's movement, issues of disability have been overlooked.

Implementing international conventions and development frameworks

The United Nations Millennium Development Goals (MDGs) and the Biwako Millennium Framework (BMF) should inform government actions in Australia as it does in the rest of the Asia-Pacific region. As a country which has ratified the UN Convention on the Elimination of all forms of Discrimination Against Women (CEDAW), and in keeping with Special

Recommendation No. 18 of 1991, the Australian Government should also routinely address and report on actions to improve the status of women with disability in health services, social security, education and employment. Up to and including 2005, this had not been the case.

On 17 July 2008, Australia ratified the UN Convention on the Rights of Persons with Disabilities (CRPD). The CRPD makes specific mention of the vulnerability of women with disability in Paragraph (q) of the Preamble:

Recognizing that women and girls with disabilities are often at greater risk, both within and outside the home, of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation (UN nd).

The CRPD Article 6: Women with Disabilities, reiterates this sentiment and expands on the need to address the multiple discrimination experienced by women with disability. Importantly, this Convention does not merely outline the human rights of persons with disability, it also serves as a code for implementation of these rights. Implementation of the CRPD must include specific targets to address the low status of women with disability.

CEDAW and the CRPD are the primary tools used by WWDA to address both gender and disability discrimination in the workplace to improve the status of women with disability. However, WWDA's work is also underpinned by a raft of UN human rights declarations and conventions,¹ especially those to which Australia is party.

WWDA primarily works within Australia, but it is able to provide mentoring support and resources to significant numbers of organisations of women with disability in the Pacific Islands and Asia. WWDA also works cooperatively with sister organisations in Europe and North America, and is a foundation member of a new global network, International Women with Disabilities (INWWD), which will work internationally to address the low status of women with disability.

New advocacy models

The societal, cultural and attitudinal disadvantages faced by women with disability create a great need for concerted systemic advocacy. Traditionally, systemic advocacy in the field of disability in Australia has been 'bundled' or 'mass' individual advocacy, where professionals and others have acted upon issues deemed to be in 'the best interests' of those with disability.

This is a perpetuation of the old charity and service models of ministering favours to people with disability because they are 'less fortunate', even 'cursed', and unable to do it for themselves. Such an advocacy paradigm persists subliminally in some disability service organisations (DSOs) and overtly

in others. This form of advocacy is outdated, paternalistic and inconsistent with a human rights approach (Clear 2000; Dowse 2007; WWDA 2007b). Tokenistic attempts at change often result in superficial alterations but little movement in the actual power hierarchy.

Empowering women with disability in Australia requires funding of appropriate support structures to enable the women to advocate for themselves. The new characteristics of advocacy for women with disability are that the women speak and act in their own interests. There is a need for them to be able to work through collectives which have a basis in self-determination. It is important that the women know that the rights for which they fight are internationally validated through the various UN conventions. It is also important that female advocates with disability are imbued with a sense of their own personal worth and autonomy. This is equally as valuable a function of advocacy as achieving social inclusion and change.

Systemic advocacy work needs to be multi-faceted, employing a range of methods. The strategies employed could be utilised by formal lobbyists to government and are applicable in both developed and developing countries. Government funding structures of DPOs in Australia tie key performance indicators to a range of activities, which reflect the following categories of systemic advocacy.

Policy and programme input

In Australia, the majority of input to policy and programme development, review and critique is made through submissions to government in response to formal inquiries. Since discrimination against women with disability encompasses all facets of society, responding to inquiries, and at times initiating action, can account for a large proportion of staff energy and time.

In 2008, the new Federal Government endeavoured to address the social inequities outlined in its pre-election platform, and a large number of initiatives have almost simultaneously commenced. WWDA has contributed to Government discussion papers on violence against women, social inclusion, homelessness, the national disability strategy, telecommunications regulation, and AusAID's disability policy. It has also produced a general policy paper on WWDA's human rights framework for systemic advocacy.

Agitating for legal reform

Access to the legal system for women with disability is extremely difficult. The physical barriers to access such as a lack of ramps, absence of hearing augmentation and unavailability of Auslan interpreters are matched by attitudinal barriers where victim's accounts are disbelieved and discounted. This is compounded by the need for reform in the substance of the laws themselves.

For example, there is a need for uniform national legislation which will prohibit the sterilisation of women and children with decision-making disability, except in cases where there is a threat to life. A prolonged, intense campaign by WWDA, supported by the UN Refugee Agency and United Nations Children's Fund has helped prevent the adoption of new, drastically flawed legislation but has not yet been successful in promoting the drafting of an acceptable substitute. The campaign continues via post, email and direct representation to officials and Government Ministers.

Research and consultation

For an under-resourced community organisation, and most DPOs fall in this category, there is little capacity to conduct research. Specific grants must be found to do any work in this area. Alternatively, an NGO can facilitate research, assist in identifying participants, convene focus groups, and disseminate results on an ad hoc basis for other organisations. An NGO can also have direct access to and ownership of research findings.

Development of resources

The scope for development of electronic resources has vastly improved this area of systemic advocacy. However, many women with disability have limited access to information and communication technologies. Thus, resources need to be provided in a variety of formats.

DPOs need to develop their capacity to act as a conduit of information from constituents to government and vice versa. Capacity building to enable development and maintenance of an informative, accessible website becomes an extremely cost-effective way of making resources available to the wider world.

The WWDA website, www.wwda.org.au, hosts a large library of articles, submissions and information, and is a portal for human rights information. The website has about 800,000 visitors per year, thereby reaching more people than could ever be achieved through hardcopy resources.

Direct lobbying

DPOs need to pro-actively nurture links with politicians and their key staff members, principally those in government ministries, but including those in opposition and minor parties. Strong allies may be found in the latter positions.

Initial contact can be a daunting challenge for the uninitiated, non-professional lobbyist. Mentoring partnerships with more experienced advocates in other NGOs can be helpful. Delegations should comprise several members with an appointed lead discussant, and a note taker. It is important that the discussion is summarised and any agreed actions noted, and a timeframe for achieving outcomes decided before the meeting is closed.

Community education and representation

Visibility in the community is important, with a need for advocates to be presenters at forums and conferences, and to be involved in both mainstream and special interest organisations. Many government departments and agencies, as well as private enterprise organisations, maintain their engagement with constituents via advisory boards. Therefore it is important for systemic advocates to secure positions on boards which have jurisdiction in areas where change needs to be made.

Where gaining membership of a desired advisory group fails, it is necessary to form allies among the group's members. For women with disability, the list of strategic government advisory bodies is long, including those in the areas of violence, social inclusion, homelessness, education, telecommunications, welfare, employment, health services, preventative health and human rights.

In the digital age, there is potential for international networking, as is the case with the formation of INWWD in August 2008 in Quebec City. This was an outcome of the first Global Summit of Women with Disabilities held in conjunction with the 21st Rehabilitation International Conference.

Information dissemination

To a degree, all activities undertaken by any woman with disability could be classed as systemic advocacy, since it will contribute in some way to raising awareness of the issues faced by this group. The more targetted the action, however, the greater the likely impact to bring about systemic change.

Conclusion

Systemic advocacy is an essential ingredient in the work of those who aim for social justice and the human rights of all citizens. For women with disability, the activities outlined here are components of that work. Empowering women with disability to undertake systemic advocacy has systemic challenges. Low status in society usually results not only extreme poverty, but extreme emotional fragility.

Self-esteem and self-belief must be built up before a woman with disability will be able to effectively address the inadequacies of an entrenched system. Capacity building through collectivism, mentoring and training is necessary. Long-term monetary support from government is needed, supplemented where possible through philanthropic or corporate donations.

Although there are not yet sufficient women advocates with disability for the tasks at hand, their numbers are increasing. Leadership and funding will need to come from the highest levels of government, however.

The CRPD, backed by CEDAW, the MDGs and BMF provide the blueprints and impact assessment tools for all policies and programmes of governments, industry and community

organisations. It is time now for change, and the insistent prompts for action will come from women with disability forming a chorus of 'voices for change' which can no longer go unheeded.

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Note

1. Universal Declaration of Human Rights, Covenant on Civil and Political Rights, Optional Protocol to the Covenant on Civil and Political Rights, Covenant on Economic, Social, and Cultural Rights, Convention Against Torture, Convention Against Genocide, The Geneva Conventions, Convention on the Rights of the Child, Convention on Elimination of Discrimination Against Women, Declaration on the Rights of Indigenous Peoples, Charter of the United Nations.

Women with disability and HIV vulnerability in northeast India: A qualitative investigation

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Background

The Indian census of 2001 found that 2.2 per cent of the country's 1.1 billion people were living with a disability (Government of India 2001). Disability organisations contend this figure is an underestimate due to widespread stigmatisation of disability, and suggest five–six per cent is more accurate (Thomas 2005). In 2006 there were approximately 2.47 million people living with HIV in India, with a national prevalence among adults estimated at 0.36 per cent (NACO 2008) and large variations across the vast sub-continent (Steinbrook 2007).

There is evidence that limited access to economic and educational opportunities — as often experienced by people with disability — may increase HIV vulnerability (Rani and Lule 2004; Luke 2006). Despite this theoretical link, there is little international or Indian research on HIV prevalence, risk and vulnerability among people with disability, or on the extent to which HIV programmes have addressed their needs (see PMO-DFID 2007). A review on mainstreaming disability into development programmes in India (Thomas 2005) found close links between poverty and disability; it also noted that gender norms for women created additional barriers to the social advancement of girls and women with disability. Women typically comprise over half of HIV-infected people in advanced epidemics; this is attributed to their greater physiological vulnerability and to gender inequalities that heighten their exposure to risk factors (UNAIDS 2006). It is important to redress research gaps in order to illuminate connections between disability, gender and HIV vulnerability.

Manipur and Nagaland, in India's northeast, are ethnically diverse states where protracted insurgencies and economic stagnation present challenges to development. The HIV prevalence is much greater than the national average, particularly among injecting drug users (IDUs) and female sex workers (FSWs) (Chandrasekaran et al 2006). Most HIV programmes focus primarily on recognised risk groups.

With support from the UK Department for International Development, a research project (2006-07) was implemented by the University of Melbourne (Australia), the Emmanuel Hospital Association (EHA), India, and research partners in Manipur and Nagaland. The study aimed to develop practical guidelines to make HIV programmes in Manipur and Nagaland more disability friendly. Objectives were to: 1) explore HIV

vulnerability and risk perceptions for people with disability; and 2) identify HIV-related education and service needs and preferences of people with disability. The guidelines (2007) have been published, and overall findings reported elsewhere (Morrow et al 2007). This paper summarises findings related to gender and HIV vulnerability, and opportunities for HIV prevention among women with disability.

Study design

The study used primarily qualitative tools and participatory approaches in each state over several phases (see Morrow et al 2007). Participation of people with disability in each phase was a notable feature; we sought input from individuals with a range of disabilities and socio-demographic backgrounds to reflect some of this population's diversity. Representatives from disability and HIV/AIDS sectors also participated.

Phase I in each state involved a consultative workshop with people with disability and providers of disability services to expand concepts, followed by Focus Group Discussions (FGDs) and semi-structured individual interviews (IDIs), using loose question guides, with urban-based people with disability aged 18-35. Participants were recruited through the workshops, disability organisations and snowballing. In each state we held one FGD with HIV programmers (recruited through our collaborative HIV prevention program, Project ORCHID), and three IDIs with representatives of disability organisations. Facilitators and interviewers were the same sex as people with disability informants and used the local language. FGDs and IDIs were audio-taped, transcribed and translated into English. Thematic analysis, based on study objectives and categories of enquiry, was used to analyse qualitative data; gender-related themes were the special focus for analysis for this paper.

Following Phase I analysis, we convened workshops in each state for people with disability and providers of disability and HIV programs to disseminate findings and draft the disability-friendly guidelines (Phase II). The guidelines were refined with input from the international literature and additional workshops (Phase III).

The study was approved by the University of Melbourne's Human Research Ethics Committee and the EHA Institutional Review Board. Participants were given information sheets in

which the confidentiality and voluntariness of participation was made clear. Informed consent was obtained and no inducements were given.

Findings and discussion

Findings on HIV awareness did not vary by sex, and are reported elsewhere (Morrow et al 2007). In presenting gender-related findings here, we acknowledge the complexity of discerning whether particular responses from or about women were expressions of gender, or simply reflected a range of human experience. We hope the reader will give allowances for the fine line that exists and the difficulties in attribution.

Details on demographic background and type of disability among the sample of people with disability appear in Tables 1 and 2.

Note: The code number of each focus group discussion (FGD) and structured individual interview (IDI) is used to indicate the source of quotes.

Participants were invited to comment on HIV 'vulnerability' (ie, the potential for risk) for males and females with different disabilities and life circumstances. While stigma and social exclusion were thought to influence vulnerability for both

sexes, these and other impacts on women were typically described in relation to prevailing gender roles and local cultural expectations.

Gender, social exclusion and HIV prevention

High levels of stigma exist in northeast India in relation to disability. In Manipur, pregnant women avoid gazing at people with disability for fear that her infant will be born disabled; many also believe disability is an outward punishment for sin.

They performed many kinds of rituals, thinking that [my disability] was the work of an evil spirit. I was not born handicapped ... I used to feel ashamed I have heard people laughing at me due to my disabled legs ... but then, what to do? I kept quiet (M3).

People with disability from both states reported feeling shunned by neighbours and the broader community.

Sometimes I feel ashamed. I am not like others ... so I don't go out (N2).

Table 1: FGD demographics

FGD code	State	No. (sex) of participants	Type of disability	Age in years	Marital status	Educational level
1	Manipur	6 (F)	Blind	18-25	2 married 1 divorced 3 unmarried	2 undergraduate 1 graduate 3 secondary
2	Manipur	6 (F)	Physical	26-35	1 married 4 unmarried 1 widow	4 primary 2 secondary
3	Manipur	7 (M)	Blind	26-35	2 married 3 unmarried 2 missing	4 secondary 3 undergraduate
4	Manipur	6 (M)	Physical	18-25	1 married 5 unmarried	4 secondary 2 undergraduate
5 6	Nagaland	5 (F)	Blind	18-25	5 unmarried	missing
6 7	Nagaland	6 (F)	Physical	26-32	1 married 5 unmarried	all literate
7 8	Nagaland	6 (M)	Blind	26-35	3 married 3 unmarried	2 illiterate 2 secondary 1 higher secondary 1 undergraduate
8 9	Nagaland	6 (M)	Physical	18-25	6 unmarried	2 primary 1 secondary 2 higher secondary 1 undergraduate

Table 2: IDI demographics

IDI code	State	Sex	Type of disability	Age in years	Marital status	Educational level
M 1	Manipur	F	Blind	26	Unmarried	Secondary
M 2	Manipur	F	Physical	35	Unmarried	Higher secondary
M 3	Manipur	F	Physical	35	Widow	Higher secondary
M 4	Manipur	M	Blind	28	Married	Secondary
M 5	Manipur	M	Physical	18	Unmarried	Secondary
M 6	Manipur	M	Physical	34	Unmarried	Secondary
N 1	Nagaland	F	Physical	27	Unmarried	Higher secondary
N 2	Nagaland	F	Physical	23	Unmarried	Illiterate
N 3	Nagaland	M	Blind	35	Unmarried	Higher secondary
N 4	Nagaland	M	Physical	28	Unmarried	Undergraduate
N 5	Nagaland	M	Physical	21	Married	Illiterate

Hiding of disabled children by family members was frequently mentioned. As a representative from a Manipur intellectual disability organisation explained:

Suppose ... there is a mentally retarded child and I went up to them to do something good for the child. When you ask whether they have a child who is mentally retarded they might scold and send you away. 'Why are you asking? ... Did you come to embarrass us?' ... [They] will not bring out their child thinking that others will tease them ... Even if they call a doctor they will do so in the evening ... so that others will not see the doctor entering. This is because of stigma and because of this barrier it is very difficult to reach this marginalised group.

Girls in India generally receive less education than boys. According to our participants, most girls with disability were poorly educated or illiterate.

There is a small girl who ... has been gradually losing her eyesight ... So, her mother hides her... I went to her place and told her mother repeatedly to send that girl to the blind school. But her mother refused ... thinking that she could never get married (divorcee, 25, FGD1).

Social exclusion limited women's mobility and non-formal learning opportunities. Participants voiced concerns that 'hiding' or a sense of shame prevented people with disability from attending community HIV meetings, a popular strategy in northeast India. And despite widespread awareness of the right to education or information, physical impairments meant that many who wished to access HIV programmes were unable to do so.

We have our own rights ... equal opportunity rights for participation ... But there are none to guide us ... We cannot go around as normal people do. And [so] our knowledge is a little less (M1).

Others noted the difficulties for poorly educated people with disability in understanding HIV messages. Respondents agreed that existing HIV educational models are not designed to reach people with disability. Some also reported widespread perceptions that people with disability did not need prevention programmes based on assumptions that they were housebound and not sexually active.

Maybe nobody bothered about informing [people with disability] ... There are some disabled whose family and friends might think 'they are disabled, they don't need awareness' (N1).

Sexual transmission risks

Research elsewhere has found that many guardians fail to recognise HIV information and service needs of people with disability, who are often (sometimes incorrectly) perceived as not sexually active (Groce 2004; Wazakili et al 2006). Study participants contradicted assumptions that females with disability are not sexually vulnerable to HIV. A number mentioned the 'tradition' of some (uneducated) deaf women to become sex workers. Given that no HIV outreach to the hearing-impaired existed, such women were at real transmission risk in a setting of relatively high HIV prevalence. Homelessness, likely to be more common among people with disability due to illiteracy and joblessness, was also seen as a risk factor for women.

Some others are just roaming in the streets, sleeping in the streets, street women, beggars — this group have more chance

of getting infected with HIV through raping by some other beggars, rag-pickers ... (FGD Nagaland HIV organisation).

Intellectual disability makes girls and women 'soft targets', according to participants from disability organisations.

Disabled persons are more vulnerable according to the newspapers and reports ... these mentally retarded girls, they are mainly sexually exploited ... One way is they can be physically aroused and ... don't know whether it is good or bad, or they follow their physical drive ... Another one is [sexual assault] ... So ... naturally the chance of HIV infection or STI or unwanted pregnancy is very high (Manipur intellectual disability organisation representative).

Hearing, vision and mobility impairments make women less able to flee or resist, compounding the fear many women experience about being overpowered. Some people with disability described their constant anxiety over potential sexual assault for its own sake, and for cultural reasons. Traditional expectations of female rectitude and virginity at marriage remain widespread, creating pressures on girls and women to remain close to home to perform household tasks and avoid being seen as 'loose'. For those with disability, these strictures are enhanced by family protectiveness. A woman who has been raped will find it extremely difficult to marry. One blind woman explained these inter-connections and intense social barriers to help-seeking:

We may either be trapped or kidnapped ... because we do not see anything. Therefore, we are very much afraid about that ... When we go at night with someone who is not our family member, we are scared ... We are hesitant to go to remote places because people recognise that we are blind ... Just imagine that I have been raped. I would probably have a suspicion about contracting HIV if the rapist is [thought] a drug user. Now [imagine] I am a blind unmarried girl who had been raped. But I still want to get married. But in this situation who will like to marry me except for some generous persons? So I have to face four situations now. Firstly, I am blind. Secondly, I have been raped. Thirdly, there is uncertainty for my marriage. And finally, there is risk of HIV infection. Therefore, I will need a confidential centre ... [or I] could never [otherwise]... disclose (divorcee, 25, FGD1).

In India, most marriages are arranged. FGD participants reported cases where families of HIV-infected men sought to marry them off rapidly to ensure they would have at least one child before the illness claimed them. Respondents feared being duped in this way (given their reduced marriage prospects) and

lamented the lack of mandatory pre-marriage HIV testing. Our sample included a physically disabled woman who contracted HIV in this way. Now a widow, the in-laws — who blamed her for his illness — tried to evict her from the family home with her child.

They blame me for everything. Women are often blamed for such problems, aren't they? There are many cases like this. The wives got infected from their husbands but the wives are blamed ... My mother-in-law asked me to leave home after my husband's death ... They don't want a handicapped to be their daughter-in-law (M3).

Obstacles to receiving HIV-related services

Stigma, isolation and gender not only enhance HIV vulnerability for people with disability, but are barriers to accessing HIV services. Although Manipur and Nagaland have voluntary counselling and testing centres, these may not ensure confidentiality for people with disability: '[For] general people ... [one] can easily go to the private clinic and test one's blood. They can also do this secretly. But for us it is going to be very difficult because people will surely know us.' A vision-impaired woman speculated on challenges in accessing services at a major centre for those with sight or mobility impairments:

It is heard that services are done at the first floor of the [hospital] ... Suppose a disabled woman of 35 is brought to the centre. Then who will carry her upstairs? (divorcee, 25, FGD1).

Unless services are accessible and comprehensible to those with different disabilities, they will not meet the needs of people with disability. As well, fears of loss of reputation from being identified would deter individuals, particularly unmarried women and their families, from care seeking.

Opportunities for delivering HIV programmes to women with disability

Study participants revealed an awareness of rights, determination to confront stigma and ideas for delivery of HIV programmes. Admittedly, respondents were urban-based and most had education, but there is a growing national discussion on human rights and numerous Indian organisations are committed to human rights' protection. It was also clear that for some aspects, gender and cultural sensitivity are crucial for uptake and effectiveness.

The first challenge is to identify and locate people with disability. A lack of comprehensive population data adds to people with disability's 'invisibility' to HIV outreach workers.

Disability service providers and local leaders are likely to be aware of people with disability within a given area. This is one reason offered by respondents to build partnerships between leaders and organisations that deliver HIV or disability programmes. Another is that the disability sector understands the context of people with disability and can communicate more effectively.

It is inefficient and perhaps ineffective for HIV programmers to attempt to expand their focus to this sub-population; however, to use disability workers for HIV education requires that they know the topic and accept its relevance. Given that a few workshop participants working in disability voiced scepticism about people with disability's need for HIV prevention, awareness-raising is important.

The second and obvious necessity raised by participants was for information materials that are accessible to people with different types of disability (eg, through sign language or in Braille), and are also entertaining. Television, radio, print, drama and special meetings for people with disability were mentioned as vehicles.

Nearly every participant with disability agreed on the advantages and even necessity of peer education for HIV prevention. Peer HIV outreach has been utilised successfully elsewhere in India (Basu et al 2004; Sivaram and Celentano 2003). Preference for a peer approach is hardly surprising given the stigma attaching to disability, fear of humiliation and the desire to feel affirmed and understood.

We don't need special educators ... Yah! Everyone can do it. I mean if I am aware about HIV, how ... it is prevented, then I can tell you or give awareness ... That is why, though I am not qualified for this, I can know (N1).

One participant noted the additional benefit to the educator of increased self-esteem and the capacity to be a role model to other people with disability. One noted the beneficial impact on families through direct contact with people with disability who move beyond the home environment to deliver HIV education.

Whatever we want to do we can go from house to house. Those parents who told their children not to go out, when they saw us they want their children also to go out (M2).

For the female intellectually disabled, two approaches were recommended. Firstly, a culturally-appropriate activity, possibly conducted by church or local leaders, could raise community awareness of their vulnerability to sexual exploitation, and the responsibility of all members to offer protection and to safeguard their human rights.

The message should be that they should not be laughed at; it is not because they have committed sin, not because they are guilty ... They should be accepted, they should be given support ... If the localities think 'Oh! This small girl is mentally weak,' ... she is vulnerable. Young boys will tease her or molest her. If they have such knowledge then even though they are not the exact family they might help her or protect her. Thus, there is a role for the localities (Manipur intellectual disability organisation representative).

Secondly, the family should be the primary educational target, though this demands great sensitivity (ideally via trusted individuals within local organisations) to reduce the likelihood of offence or misunderstanding from the family, who may see such approaches as implicit accusation of ill-treatment.

Several respondents felt distinct services for people with disability would be more user-friendly.

I mean if a department or a provision is set apart for the people with disability it becomes easier to approach ... it's more accessible. They won't have any, you know, hesitation in getting those services and things like that (N1).

Others, however, feared that separate services could increase stigma by implying that people with disability engage in HIV-risk behaviours. To increase confidentiality of services, it was suggested that special helpers be designated to assist with communication, transportation and physical needs on arrival at the facility.

HIV programme providers noted that, with small adjustments, their activities could be made more accessible or appropriate. But others stressed that funding constraints restricted their focus to nominated high-risk groups, while still others worried that their skills were inadequate to addressing disparate needs of people with disability.

... Because the services we provide now are for sex workers, [drug users, etc] ... but disabled-handicapped category is not there ... I think we must be trained. But training is also not enough. We have to meet their needs and to do that we need financial assistance (FGD Nagaland HIV organisation).

Study limitations

There are several limitations to the study. Firstly, the sample was not random and cannot be said to be representative of people with disability. Moreover, participants were recruited through disability organisations, with some bias towards the more educated. However, our findings are broadly consistent with those from other settings. Secondly, findings relate primarily to those with physical or visual impairments. Finally, we did

not seek to produce quantitative data on HIV prevalence or risk among people with disability. The acute lack of data in this area underscores a need for further research.

Conclusion

Other research in India found people with disability experienced difficulty accessing various community services, including health services, due to: lack of awareness of their rights and available programmes; physical barriers limiting access; and attitudes of health professionals and community (Pal et al 2000; Robins et al 2006). The increasing HIV prevalence in Nagaland and Manipur has prompted calls for an 'integrated and all-inclusive' response (Godbole and Mehendale 2005); we argue this should include the needs of people with disability.

Greater visibility and activism of disability organisations is crucial for advocacy, while there are potential benefits from partnerships across the HIV and disability sectors. A recent national survey revealed that among people with disability 55 per cent were illiterate, nine per cent had secondary schooling, and 26 per cent were employed (NSS 2003). Research shows that formal education can reduce HIV vulnerability among non-disabled populations (Bankole et al 2004; IIEP 2003), and presumably would have similar effects for people with disability.

Short-term gains are possible through awareness-raising and advocacy, while long-term improvements rely on the provision of education and employment opportunities to people with disability. Given the greater disadvantage experienced in general by girls and women in India, and by people with disability, activism through women's organisations to address HIV prevention needs for girls and women with disability is both timely and crucial.

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What kinds of support do women with disability need?

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Introduction

In Vanuatu, an estimated 99 per cent of care and support to women with disability is provided by immediate families, and almost exclusively, female family members. Programmes specifically tailored for women with disability are non-existent. Integration of services within existing structures can take place, but it requires awareness from disability organisations.

Only in the last 10 years, through coordinated and systematic advocacy, has the Government of Vanuatu become more aware of the marginalisation of people with disability and their exclusion in national programmes, including services. This awareness has prompted improvements in service delivery. In one significant move, Vanuatu became the first Oceanic country to ratify the United Nations Convention on the Rights of Persons with Disabilities, on 23 April 2008. This was the first huge step, and many more smaller steps will be needed to address existing inequities.

Population

Vanuatu is a small Pacific Island nation where approximately 78 per cent of the population lives in rural areas on the 65 small islands which spread over a 1,000 kilometre radius from Torres in the north to Tafea in the south.

The estimated population in 2008 was around 229,423 of whom 112,309 were women (National Statistics Office 2008:2). If we go by the World Health Organization estimate that 10 per cent of any given population has disability, then the number of people with disability in Vanuatu is approximately 22,942. At least 49 per cent, or 11,471 will be women.

Available support

Information about where people with disability reside, their activity limitations, their barriers to social participation, and the type of support they receive or require is not available. In Vanuatu, support in general — such as counselling for assault victims, pre- and post-operative counselling for amputees and their families, support for accessing education and training, employment, self-improvement — is either not available or not accessible to women with disability. Government agencies provide most basic services, but NGOs and churches fill gaps in basic service delivery.

The Vanuatu Society for Disabled People is a community-based rehabilitation organisation (CBR) responsible for providing services for people with disability. Since it began

operating as a CBR in 2001, there has been no specific support programmes for women with disability.

It is widely believed that the family acts as a safety net and provides the services and support needed by family members, with or without disability. While this was the case in the past, these safety nets are eroding due a number of factors, including:

- growth in migration from rural to urban centres;
- increased squatter settlement populations lacking traditional family support;
- growth of urban employment centres;
- rise in unemployment particularly among the youth;
- limited job opportunities for people with disability;
- increased move towards cash economy; and
- decreased delivery of services to the rural population.

Support needs

The following case studies bring to light some of the injustices yet to be addressed by disabled peoples organisations (DPOs) and government.

Denial of right to safety

Suzie is in her mid-40s. She is a quadriplegic, resulting from an incident occurring 21 years ago, when her current partner threw her over a bridge. She is a qualified teacher with two children from her first partner. She had one child with her current partner, before she became a quadriplegic, and delivered twins after the accident. Her partner is unable to support her, so she is cared for by religious organisations and lives on their premises.

Denial of right to marry

Josie has multiple limb deficits and requires 24-hour assistance. She has worked for the Government for the past 25 years, lives in Government accommodation with her siblings, and was supported by her mother until recently, when her married sister took over that role. In 2004, she informed her parents that she had found a man who wanted to marry her. Immediately, her parents provided reasons why she shouldn't marry: she has a disability, he would not know how to look after her, she might get beaten, how would she look after any children? Despite her

stance that she was old enough to make her own decisions, and wanted to marry this man, the barriers imposed by her family were too great. The opportunity to marry slipped by.

Denial of right to education

Sonya was aged 15 and in Grade 8 when she became deaf as a result of malaria. Upon returning to school, she was told that she could no longer continue her education, due to her impairment. Approaches made to the special needs officer of the Department of Education fell on dry ground. Sonya has been denied her right to education because the education system cannot support children with disability in school, contrary to the Education Act and the Convention on the Rights of the Child which Vanuatu ratified in 1993.

Useful strategies for mainstreaming disability

Although a small advocacy group, our efforts over the last nine years have largely been directed at government and aimed squarely at putting disability on the national agenda. What is provided below draws on some lessons learnt as to how we have attempted to mainstream disability, with some lessons drawn from attempts to mainstream gender in Vanuatu.

Since its inception in October 1998, and its establishment as an NGO on 4 April 1999, the Disability Promotion and Advocacy Association (DPA) has had three aims:

1. to advocate for rights and promote abilities of people with disability;
2. to put disability on the agenda of the national Government; and
3. to create attitudinal changes within the general public that people with disability have the same rights as everyone else: no more, no less.

In doing so, we recognised three key players as important agents of change:

1. individual members and their families;
2. communities including the churches, women's groups, media, national and international NGOs, DPA itself; and
3. government as an institution with the power to make decisions that will realise our goals.

A three-pronged approach was therefore instituted utilising our aims for these three agents of change:

1. Individuals

We firstly created a vision and agreed on some fundamental principles within the organisation itself to give people with disability the courage to join the organisation and be agents of change. In 1999, it was decided that DPA would be a sustainable, voluntary, self-help organisation that will

operate for five years without core funding by utilising the different skills and abilities possessed by people with disability. This has been one of *the* most profound decisions. It has shaped the organisation and those working in it.

Empowering people with disability with the knowledge that they *do* have the skills and abilities to change not only their own attitudes and perceptions — from that of recipient waiting for things to happen to change agents — but those of communities and the nation, has enabled major changes. A small group of people with disability began to emerge and become self advocates. Now, the message that people with disability have rights is being heard in Vanuatu.

Commitment

Wensio Tom is from southwest Malekula, central Vanuatu. He joined DPA in 2002. Using only his walking stick, because his legs are permanently bent at his knees, and armed with a firm belief in DPA's vision and mission, he walked the southwest bay area of Malekula advocating for rights of people with disability.

Without any financial or material support from DPA, he slept under trees and in copra sheds and lived off coconuts or through the generosity of people he visited to advocate for rights of people with disability, collecting statistics and generally empowering people with disability. He thus established three community-based DPOs. In 2007, his commitment was recognised and he was appointed provincial advocator.

Knowledge

Marian Paialeles joined DPA in April 2005. During a DPA meeting that same year she heard of something called rights: to be protected, to be safe, to access justice, health care and education, among others. Within six months of this meeting, she had set up a community-based DPO in her village, and was raising awareness and advocating to people within her communities to recognise the rights of people with disability.

In the same year, she established the first inclusive kindergarten in the village of Narango in South Santo. She took in children with disability who were not attending kindergarten because teachers did not know how to look after them or did not think children with disability should be attending school.

2. Communities

Within communities, there are a number of different groups which DPA members and volunteer staff lobby for recognition of the rights of people with disability. DPA uses the International Day of Persons with Disabilities, on 3 December, to celebrate and pass on the message of rights of people with disability. Thousands of people in five of the country's provinces have been reached through this approach.

3. Government

In the absence of policies and programmes for people with disability we have relied heavily on national, regional and international government commitments. These commitments include United Nations Conventions such as the Elimination of All Forms of Discrimination against Women and the Rights of the Child, Declarations such as the Millennium Development Goals, Education for All, Biwako Millennium Framework (BMF), the Pacific Plan, and the prioritised national plan of action 2006-2015. In particular, our calls on Government to mainstream disability have reflected the BMF's seven priority areas.

Women with disability

The following are a few lessons that we have learned from our journey in Vanuatu.

Urgent legislative reform

To mainstream disability and provide support to women with disability, there is a need to constantly lobby and create awareness among all sectors of the nation using commitments agreed to by Government. While we have succeeded to some extent in getting policies drafted and some recognition of the need to include disability in national programmes, there remain underlying practices that hinder our attempts to provide specific support to women with disability.

Changing cultural beliefs and notions about women's roles is a challenge requiring partnership with government, chiefs, women, religious bodies, NGOs and donors. Decision making through consultation, requiring universal agreement by all stakeholders, is a strategy that we have used in DPA over the past five years.

Legislation, policies and strategies developed by government, as well as a fundamental shift in attitudes to recognise women as having equal capacity with men, is required. Thus we need to acknowledge the spiritual dimensions of development of human beings and recognise human beings as spiritual in nature.

Both material and spiritual dimensions of development must be addressed if we are to eradicate prejudices based on the sex of a person or the language, religion or beliefs they hold. We need to allocate resources to enable girls and women to participate and to develop. The challenge now is how to create the social, material, structural and spiritual milieu in which *all* women and girls can develop to their full potential (Bahá'í International Community 2006).

Monitoring national commitments

Using the reporting requirement for the Millennium Development Goals, for example, DPOs can evaluate progress toward mainstreaming disability. Such documents include the

United Nation's *Disability Handbook for Parliamentarians*, the Millennium Development Goals, and the BMF.

Data collection and information sharing

A friend once said that statistics will not feed the mouths of people with disability. This statement rings even truer when statistics are not gender disaggregated, because decision makers require this type of detailed information to build a base for their policies. We need to move beyond just disaggregating data by gender. We need to dig deeper and examine the specific limitations imposed by society, including structural and governance barriers. And we need to widely disseminate our findings.

Disability focal points

Having a disability focal point within government is vital, as is a disability strategy with the requisite human, material and financial resources in national budgets, with clear goals, and outcome results with specific timeframes to measure achievements. Gender perspectives can be incorporated within this strategy.

Partnership

Partnership with civil society organisations and with the media has been very fruitful for us in Vanuatu. Forming a coalition with like-minded NGOs to advocate for issues of common concern is very useful. Supporting such groups goes to the very heart of ridding our society of structural prejudices.

Another vital link is partnerships with regional and international organisations. For example, Vanuatu's commitment to international peace has seen it become party to the Ottawa Convention of 2005. Since February 2008, Vanuatu has endorsed both the Wellington Declaration and draft treaty on the banning of cluster munitions. These weapons create mass destruction of lives and limbs. The disability sector must support campaigns to ban such weapons and convince our governments to sign such treaties.

Disability Convention

The provisions of the United Nations Convention on the Rights of Persons with Disabilities are to be realised progressively. Thus, it is important not to be discouraged if government does not act as quickly as we would like. We must continue to be vigilant and assist where we can. For example, lobbying for the introduction of universal design provisions, and ensuring that there are ways in which the application of these laws are followed and monitored, should not be too difficult. Others, such as changing attitudes and prejudices built over centuries, will be more difficult to change overnight.

Building women's capacity

It is important that women's sections within DPOs are strengthened. Fundamental to this is the need for a gender policy including strategies to address discrimination against women with disability, and ways to develop their capacities.

Conclusion

People with disability are an integral part of society whose needs and aspirations are the same as those without an obvious disability. Inclusion of people with disability in development programmes cannot be separated from national programmes. Advancing women with disability and providing support for them will require the removal of long held prejudices based on sex, race, disability, language and ethnicity.

At the root of our efforts to eradicate discrimination and build a society that is just, free from prejudices and inclusive of all men and women, is the notion of the oneness of humanity:

The world of humanity has two wings — one is women and the other men. Not until both wings are equally developed can the bird fly. Should one wing remain weak, flight is impossible. Not until the world of women becomes equal to the world of men in the acquisition of virtues and perfections can success and prosperity be attained as they ought to be (Abdu'l-Bahá, in Ferraby 1997:97-98).

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Inclusive education in Timor-Leste: This classroom is for everyone!

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Like many developing countries, Timor-Leste is weighing the benefits of inclusive education with the apparent practical difficulties of teaching children with special learning needs in mainstream classes.

This paper presents findings from the first national survey of disability in Timor-Leste's primary schools, published in 2008. It will highlight the scale and type of disabilities reported in schools and will discuss what is required to meet the special learning needs of these children. This paper will also analyse the challenges and opportunities facing the Ministry of Education in providing a truly inclusive schooling system in Timor-Leste.

Legal obligations

The right to education for children with disability is clearly enshrined in the Constitution of Timor-Leste 2008. Section 16 (Articles 1 and 2) states that everyone has the same rights and no one shall be discriminated against, including on the grounds of 'physical or mental condition'. Children are afforded special protection against all types of discrimination (Section 18, Article 1) and the State is given responsibility for ensuring all people (including those with disability) have access to the highest level of education, in accordance with their abilities (Section 59, Articles 1, 2 and 4).

Timor-Leste is also a signatory to a number of international conventions that prohibit discrimination on the grounds of disability and protect the right to education for children with disability. An April 2008 survey, however, estimates that only one in 10 children with disability attends primary school (Plan 2008). This is a stark reminder that the realisation of these rights will require a major commitment from the Government of Timor-Leste and its development partners in the coming years.

Education in Timor-Leste

By 2015, the Ministry of Education wants every child to attend and complete six years of primary education. This is an ambitious and commendable goal for a country that saw 90 per cent of its schools seriously damaged or destroyed in the post-referendum violence of 1999.

The challenges are not confined to infrastructure. Timor-Leste has inherited an education system with few qualified teachers, overcrowded classrooms, high rates of repetition and low instruction hours (World Bank 2004). Latest figures suggest enrolment rates are rising each year (a net enrolment rate of 69

per cent and a gross enrolment rate of 87 per cent was recorded in 2005-06) but repetition rates are high at 16 per cent. What is more, the latest State of the Nation Report found that only around half of school-age children finish primary school and overall academic achievement levels are low (Xavier 2008).

Timor-Leste is undertaking wide-ranging reforms of the education sector as it strives to meet its constitutional obligations and ensure quality education for all. In doing so it must address the many barriers to full participation in the education system: poverty, distance to school, gender, language of instruction and, of course, disability. It is clear that the 2015 goal will only be met if special attention and resources are given to marginalised children, especially those with disability.

Education and disability

To date, the education of children with disability has not been prioritised. Few services exist to support families or schools (especially outside the capital Dili) and the vast majority of children with disability do not receive any education. Timor-Leste has one special school, in Dili, a legacy from Indonesian times. But enrolment rates are low — in 2008 the school had 13 students. Attendance is sporadic due to problems with transport and many of the students are older than 18 years and would be better served by supported, vocational training options.

It is clear to most that a single, under-resourced, special school in the capital cannot meet the varying needs of children with disability. Nonetheless the school has been invaluable for some students and has unique resources in the form of teachers trained in Braille and sign language. But as changes to the national schooling system are being planned, professionals in both disability and education are beginning to consider how the needs of students with disability will be met.

National survey on disability

In April 2008, Plan Timor-Leste and fellow NGO, *Asosiaun Hi'it Ema Ra'es Timor* (Association for the equality of the disabled people of Timor (ASSERT)), completed the first national survey of disability in primary schools. A quantitative study of schools (rather than of children with disability), the survey was designed to provide information to the Ministry of Education on how many children with disability currently attend regular schools across the country. The aim was to develop baseline data to help monitor the impact of future inclusive education initiatives.

Methodology

The team surveyed 336 schools across all 13 districts, representing 34 per cent of primary schools registered with the Ministry of Education's information management system (EMIS). Government and Catholic schools, large schools close to towns, as well as small remote schools were included in the sample. Data was collected on age, gender, grade, disability type and severity.

Face-to-face interviews were conducted with school directors using a standard survey form and interviewers were trained to use a series of prompts to clarify information provided. This was particularly important as disability terminology can cause some confusion in translation. For example, the most common term used for disability, *alejadu*, is often reserved for people who have an obvious physical problem affecting their arms or legs, whereas other terms such *disabilidade* or *deficiente* (disability) may be broadly interpreted as 'difficulties' and could include having economic problems or being orphaned.

All completed surveys were checked and coded by the lead investigator who allocated a disability category and severity level for each student identified by the school. Very few children with disability have ever been formally diagnosed, and even among those that have, it is unlikely that the school director would know this information.

For this reason, the study used five simple categories of functional limitation that reflected the way people spoke and thought about disability. These were: physical disability, intellectual or learning disability, problems seeing, problems hearing and problems speaking/communicating. Two additional categories were used in coding: 'other disabilities' often conditions such as epilepsy or trauma/mental health problems, and 'complex disability' used for students with more than one problem.

Teachers were asked to describe how the child performed in the classroom, and to give examples of things they could and couldn't do. Based on their open-ended responses, the disability was classed as mild or moderate/severe. This approach was informed by 'Measuring Disability Prevalence' (Mont 2007), which argues the importance of asking about functional difficulties, rather than disability diagnoses, and the need to differentiate at least two levels of severity.

The severity measure is obviously very subjective and the data associated with it should be used with caution. It is a useful indication, however, of what level of support may be needed. Children with a moderate or severe disability in any category may require additional support to ensure they are enrolled in school, stay in school and are able to learn in the classroom, while students with milder problems (who could cope well with the demands of school) may have their access to education limited because of discrimination, stigma, and community attitudes and beliefs about disability.

Results

The sample of 336 schools identified a total of 972 students (1.02 per cent) with some type of disability. Based on projected primary enrolment rates for 2008 from EMIS data, it is estimated that there are approximately 2,000 students with disability nationally, and that each school can expect to have between two and three (2.89) students with disability. There was, however, wide variation: 17.8 per cent of schools reported having no students with disability and four per cent of schools reported having 10 or more students with disability.

The sample included 285 Government schools and 51 private (usually Catholic) schools. Students with disability were significantly more likely to attend a public school but both types of schools had a similar ratio of boys to girls with disability. School size was not a good predictor of the number of students with disability, nor was there a clear relationship between the number of students with disability and proximity to town.

The most common disability type was intellectual or learning problems (24 per cent) followed by physical problems (21 per cent) and visual problems (16 per cent). There were significantly more boys with disability compared to girls (1.25 per cent compared to 0.77 per cent). However, the ratio of mild to moderate/severe disability was similar for both groups.

Primary students with disability ranged in age from five to 19 years with an average age of 10.7 years. Fourteen per cent of students with disability were 14 years or older and 41.6 per cent of students were 'over-age' (older than expected for their grade).

Findings

Estimates of disability in the general population in Timor-Leste vary widely and depend on how disability is defined. Without reliable community-level disability data it is difficult to establish how many children with disability are not in school. It has been estimated, however, that approximately 10 per cent of the global population has a disability, and that this rate is probably higher in developing countries (UN 1990).

This suggests that most children with disability in Timor-Leste are not in school. The survey data estimates that there may be up to 18,000 children with disability who should be attending primary school and are not.

What is more, the data suggests that girls with disability may be less likely to be enrolled in school and/or more likely to drop out than boys with disability. Further research is required to understand these gender differences and to determine the specific barriers to education for girls and boys with disability.

The findings on over-age enrolment are of particular concern. Timor-Leste has high rates of over-age enrolment in general, due to late entry to school, interrupted schooling and high rates of grade repetition. These trends present a considerable challenge to the efficiency of the primary education system. Nationally

it is estimated that 16-20 per cent of all students in grades 1 and 2 are repeating the school year. By grade 6, however, the over-age enrolments are much lower (around three to five per cent). Over-age enrolment for students with disability is high across all grades and highest in the older grades.

Children with disability, especially a milder disability, are as likely to start school on time as other children. The high rates of over-age enrolment appear to indicate a failure of the education system to progress students with disability through the primary grades and indicate a bottleneck at the end of primary school, suggesting a lack of appropriate secondary school and vocational options.

While the study reveals some major challenges that need addressing, it is important to highlight some positive indicators. Although a national policy on the education of children with disability does not yet exist, some children with disability are managing to go to school. When children with disability *do* go to school, they are going to their local primary school with friends and siblings. This includes students with a moderate or severe disability, and holds true for children in rural or remote areas as much as towns. These are very positive signs for the future success of inclusive education in Timor-Leste.

Recommendations

Four key recommendations emerged from the survey.

1. *A national education policy on inclusive education.*

The Ministry of Education has a duty to realise the right to education for all children in Timor-Leste and a national policy could formalise their commitment to achieving this through an inclusive education framework.

An inclusive education approach recognises that children with disability have a right to receive the support they need to attend mainstream schools and learn alongside their peers. Specialised, centralised and segregated services for children with disability will not meet the needs of most students and will be largely irrelevant for the majority of the population living in rural and remote areas. The United Nations (2007) concluded that inclusive education models are cost effective and cost efficient compared to special schools, lead to a higher quality of teaching for all students and can contribute to reducing discrimination in the community.

The national policy should outline a systematic approach to meeting the full learning needs of children with disability, including the allocation of staff and budget to this end. Both management and teaching staff will require initial orientation on the principles of inclusive education and opportunities

for continuing professional development.

Development of a national policy could also include a review of the role of Dili's special school and examine the feasibility of transforming the school into a national resource and training centre.

2. *Pre- and in-service teacher training.*

Integrating inclusive education into pre- and in-service teacher training is critical and will have the greatest impact on whether children with disability are able to reach their full learning potential. Improving the capacity and skills of primary school teachers and directors is already a priority of the Ministry of Education and providing teachers with strategies to make their classroom a more inclusive environment will benefit all students. Training on general classroom management, strategies for teaching large classes and classes of mixed ability and an awareness of multi-sensory learning are essential starting points. The survey found the most common disability in primary schools is intellectual or learning problems and that many of these students have very high rates of grade repetition (some have repeated each grade two or three times). Teachers urgently need training to support children with learning impairments and develop alternative methods of assessment as well as advice on when grade repetition is appropriate.

3. *Awareness-raising in communities.*

Promoting the rights of children with disability to attend school will be an important component of any inclusive education strategy. It should not be the sole focus, however, nor should it target parents and teachers exclusively.

Improving enrolment and retention rates in primary schools is a whole-of-community responsibility. Health workers, family health promoters and church leaders can play a crucial role in influencing community attitudes, while teachers can also do much to ensure that children with disability are genuinely welcomed at school. They can demonstrate their commitment and belief in children's ability to learn by following up with families when a child with disability is not enrolled in school (but their siblings are) or when a child with difficulties drops out. Linking with local disability NGOs and drawing on the knowledge and expertise of community-based rehabilitation networks will be vital, both to help locate children with disability and to raise awareness about inclusive education.

4. *Strengthen data collection on children with disability.*

Only by collecting data and monitoring the situation in communities and schools will it be possible to know if children are really benefiting from new laws, policies or programmes on inclusive education. This will also help Timor-Leste meet its reporting duties related to the Convention on the Rights of the Child and other human rights instruments.

Currently, there are major difficulties in accessing basic information about children in schools and an absolute lack of reliable data on numbers of 'out-of-school children' (including drop-out rates). The collection of this information is critically important to the education sector as a whole and should be prioritised.

It is also important that inclusive education issues are integrated into any future plans to strengthen and reform EMIS. At a minimum, a disability indicator should be added to the routine enrolment data collected by EMIS to assist with monitoring and planning support services. This study suggests that training of school directors will be required to develop a common understanding of disability terms to ensure the data collected is reliable.

Conclusion

Many countries have struggled for years in the long process of moving from segregated education (where students with disability are separated from their peers and taught in special schools) to a more modern, inclusive education system. Timor-Leste is currently rebuilding and restructuring its education sector. It is in a unique position to develop a truly inclusive approach to schooling that will ensure all children receive an education.

There is much work to be done at a policy level as well as within schools and communities to ensure students with disability are enrolled in primary school and teachers can provide a quality education to all their students. The results of the first national survey of disability in Timor-Leste's primary schools indicate that children with disability can and do go to regular schools and that many families recognise the value of education for all their children.

In April 2008, a sub-working group on inclusive education was established, largely led by disability advocates, demonstrating a commitment to finding ways of improving the quality of education in schools. But this is not just a disability issue.

Inclusive education models are vital in a country where large numbers of children do not go to school, drop out early or fail to learn. An inclusive education approach prioritises reaching out-of-school children, encourages schools to understand the needs of all children in the community and to find creative ways of delivering education. It begs the question: is this school really for everyone?

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Notes

1. The survey was undertaken by Plan Timor-Leste in partnership with ASSERT and the Ministry of Education, with support from Plan's Finnish national office and the Finnish Ministry of Foreign Affairs.
2. These include the UN Convention on the Rights of the Child, the International Covenant on Social, Economic and Cultural Rights and the Convention on the Elimination of All Forms of Discrimination Against Women.

Promoting disability-inclusive international volunteering: A review of Australian volunteer service providers in the Pacific

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International development cooperation has largely excluded people with disability (EC 2003:2). The benefits of development often fail to reach people with disability, and people with disability are rarely consulted or included in development activities (ADB 2005; Coleridge 1993). International volunteering has paralleled these trends; volunteers have tended to be white and able-bodied (McBride et al 2007), and disability has not been a priority area for volunteer assignments.

This paper reports on research examining the activities of Australian volunteer service providers in the disability sector across the Pacific, including Papua New Guinea (PNG). The research identified that 'best practice' inclusive volunteering would firstly utilise a rights-based approach, framed by the priorities of disabled people's organisations to promote an inclusive, barrier-free society and to achieve a range of disability-related development goals. And, secondly, best practice requires disability to be mainstreamed across volunteer assignments as well as in the internal and external policies and procedures of volunteer service providers. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the Biwako Millennium Framework (BMF) are important tools which can be used to guide the process of inclusion.

The recent ratification of the CRPD makes it timely for AusAID's volunteer programme, and the volunteer service providers who deliver the programme, to consider how people with disability and disability issues are currently included in international volunteering. Australian Volunteers International (AVI) and AusAID initiated this research which was conducted between April-June, 2008. The overarching aim of the research is to inform development practice and policy in the disability sector by exploring good programming among Australian volunteer service providers working in the Pacific.

It is well documented that people with disability are one of the poorest and most marginalised groups. The majority live in extreme and enduring poverty, with few opportunities to access basic health care, education and employment (Sarbib 2005; WHO 2006; World Bank 2007). People with disability are one of the last groups to be served by international conventions and the associated recognition and protection of rights, and many nations' laws continue to prohibit or prevent people with disability from receiving the same benefits and achieving the same living standards as others (IDRM 2005).

The international community is increasingly recognising that for development to be successful, disability must be addressed (Guernsey et al 2007).

Methods

Four volunteer service providers were examined in this research: AVI, Australian Business Volunteers, Volunteers for International Development from Australia (VIDA) and the Australian Youth Ambassadors for Development Program (AYAD). Quantitative data on the number and type of assignments in the Pacific was requested from each of the providers and where these data were available, they were analysed in terms of country of assignment, occupation, employment sector, length of stay and host organisation.

Volunteer assignment data varied considerably between agencies and accessing similar data across the agencies was not possible. Identifying disability-specific assignments and volunteers with disability was not straightforward, as information on a volunteer's impairment, particular needs or conditions has not been recorded, and disability assignments have been coded in other sectors such as health, education and governance.

Qualitative interviews were conducted with key informants, including volunteer service provider staff, returned volunteers and youth ambassadors including several wheelchair users, non-government disability-specific organisations, AusAID and other key informants in the disability and development sector in Australia. Several host organisations, organisations for people with disability and key informants in the Pacific were also interviewed.

All interviews, except those with AVI staff, were conducted over the telephone and covered a checklist of key issues. Data was analysed thematically. As reliable statistical data does not exist, this paper discusses issues raised in the qualitative data (see Gartrell 2008 for the quantitative data).

A disability forum was held in April 2008, and the preliminary findings of this review were presented to participants. Small group discussions around the six identified key themes were held and provided to participants with the opportunity to speak to those already raised and add others they felt were important. The small groups presented their ideas around the themes to the larger group for discussion. The forum validated and added contextual insights to the preliminary findings and further focused the next phase of the review.

Disability mainstreaming

Over the past decade or so, mainstreaming has become the dominant international development strategy to remove barriers preventing people with disability from being included and thereby achieving equality (Commission for Social Development 2008:5; Albert et al 2005). The recent ratification of the CRPD and the BMF provides a unique opportunity to raise awareness and to initiate development of appropriate mainstreaming policies, and more importantly, effective mainstreaming strategies and programmes to ensure the inclusion of people with disability.

The Convention is the first legally binding disability standards-setting agreement to outline state obligations to ensure the rights of people with disability. The Convention notes 'the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development' (op cit:Preambular paragraph(g)). Mainstreaming is the current international rights-based best practice approach and Australia's volunteer programme needs to adopt mainstreaming policies and strategies.

There is no officially accepted definition of mainstreaming (Albert et al 2005:36). This research adopts a reworked United Nations Development Program definition of gender mainstreaming:

... mainstreaming is the process of assessing the implications for people with disability of any planned action, including legislation, policies or programs, in any area and at all levels. It is a strategy for making the concerns and experiences of people with disability an integral part of the design, implementation, monitoring and evaluation of policies and programs in all political, economic and societal spheres, so that people with disability benefit equally and inequality is not perpetuated (cited in Albert et al 2005:6).

Currently there are few examples of disability mainstreaming in development activities (Commission for Social Development 2008). The mainstreaming model and experience of British volunteer service providers Volunteer Services Overseas (VSO) are the most relevant to this study. VSO are approaching disability mainstreaming in a structured way as an organisation, at workplace, programme and policy levels, to address and avoid increasing the negative effects of disability (VSO 2008). The VSO mainstreaming model consists of five interconnected elements — organisational commitment; sensitisation; workplace mainstreaming; policy mainstreaming and programme mainstreaming — and can inform volunteer service providers mainstreaming strategies in Australia.

VSO's experience shows that mainstreaming disability in programmes can take many forms and have many different

starting points. For example, some VSO programmes have focused on a specific impairment, such as deafness, while in others the employment of people with disability has led to workplace adjustment and sensitisation of staff, or the involvement of people with disability in programme design.

Any of the internal elements of VSO's mainstreaming model (that is, organisational commitment, sensitisation, workplace, policy and programme mainstreaming), can be valid entry points. However, the most common entry point for disability mainstreaming is through disability programmes in countries where volunteers are placed (Jones and Webster 2006).

VSO support for inclusive services has tended to focus on partner organisations, and has not always led to internal mainstreaming (ibid:10). For example, a number of VSO country programmes currently support ordinary schools to include children with disability (inclusive services), but they have not yet adjusted their own workplace policies and practices or the rest of VSO's programme work in that country (mainstreaming).

External mainstreaming in the volunteer programme

Disability has not been a priority area for assignments of the volunteer service providers in this study. To date, volunteer service providers have engaged with disability issues in an ad hoc and opportunistic manner, and none of the volunteer service providers have a policy on disability.

Following international trends, volunteer service providers began to recognise people with disability as a group with particular needs and to respond to these needs with volunteer assignments in the mid-1980s when AVI volunteers worked on disability issues in South and Southeast Asia, particularly in Bangladesh, Sri Lanka, and later in Cambodia. In the Pacific, the first disability-specific assignment saw a volunteer placed by AVI as a special education teacher with the Ofa Tui 'Amanaki Centre for Special Education in Tonga in 1998. Since then a total of 78 volunteers and youth ambassadors have been placed into positions with an explicit focus on disability.

Disability has primarily been responded to in two ways: as a health issue with the assignment of allied health professionals, and as a special education issue with the assignment of special education and inclusive education teachers. Such assignments tend to view disability as a health condition or disease to be addressed by medical or rehabilitation specialists. For example, allied health professionals (physiotherapists and occupational therapists) have been placed in training roles to support community-based rehabilitation (CBR) services in the Solomon Islands, Papua New Guinea and Fiji. Volunteers have noted that CBR services are poorly supported by the Ministries of Health, are under-resourced, and staff have high training needs.

In inclusive education, volunteers are training teachers and working to change attitudes toward inclusion. For example, a special education teacher was placed in the Solomon Islands with the Ministry of Education and the Disability Support Group. Her role was to train teachers in inclusive education. Rather than just working with the school she was placed with, she began to work at a more grassroots level surveying teachers who already had children with disability in their classes and prepared workshops to address issues concerning them. Her work resulted in approximately 90 trained teachers attending an inclusive education workshop.

Ideally, volunteer assignments in special schools should have inclusive education and mainstreaming as their broader, long-term objective. However, experience in some countries suggests that a staggered approach to inclusive education may be required, where a special needs classroom is first established and children are gradually mainstreamed. There is a danger that children with disability will follow a pathway from special schools to special vocational training and then into sheltered employment. This excludes rather than includes people with disability.

While volunteers are making valuable contributions in health and education, assignments should ideally reflect disability as a cross-cutting issue. People with disability may have issues in all sectors, not just health and education, but also housing, employment, income generation, water and sanitation, and across sectors, for example, gender and rights. It is not sufficient for volunteer service providers to only address the medical and rehabilitation dimensions of disability, or to approach disability from any perspective contrary to human rights. Approaching disability from a medical or welfare/charity model can be useful in addressing some of the spectrum of needs of people with disability (see Rhodes 2005; ADB 2005), but such initiatives must be framed first and foremost by recognition that the meeting of such needs is based on human rights.

Volunteers interviewed noted that they did not know about rights-based approaches to disability prior to their assignments and those interviewed left Australia with health-based understandings of disability and learnt about rights-based approaches through their engagement with people with disability. When volunteers are aware of the rights dimensions of disability they are able to contribute to disability advocacy, awareness raising, attitude change, inclusive community development and initiating and supporting the development of organisations for people with disability.

For example, a volunteer in the Solomon Islands identified a 'culture of becoming disabled', where the 'disability role' is to be passive and looked after by the family. Much of her work focused on changing the attitudes of family, nursing staff and people with disability, and showing them that people with disability

can play active social roles within their families.

When allied health professionals, such as this volunteer, extend their work beyond the provision of physical therapy to address broader rights-based issues like discrimination and exclusion, they deepen their contribution to inclusive development. Current assignments supporting community-based rehabilitation and inclusive education should be built upon in ways that help to remove the social barriers people with disability face to access health, education and other services and opportunities. As rights-based approaches and social models to disability recognise, the social dimensions of disability are more disabling than physical conditions (Oliver 1990), and extending the impact of volunteer placements to address rights-based issues would be valuable and international best practice.

Recently, a growing number of volunteers have been placed into advocacy and community development positions with rights-based organisations for people with disability. These assignments reflect international trends in approaches to disability, growing disability awareness of rights-based approaches in the Pacific, and the requests and priorities of host organisations. For example, the Fiji Association of the Deaf (FAD) requested a deaf volunteer fluent in Australian Sign Language (Auslan), and a deaf woman was placed to develop Fiji Sign Language and a dictionary. She worked with FAD for two and a half years and saw her role as supporting Fiji's own sign language and not imposing Auslan.

Each year a significant number of volunteers are placed into a range of sectors in the Pacific, and these could form the backbone of a cross-cutting mainstreaming approach to disability. Furthermore, rights-based approaches to disability should be included in pre-departure volunteer training to ensure all volunteers are 'disability confident'. Sensitising volunteers to issues of disability-based discrimination would enhance their capacity to contribute to longer term attitude and cultural change, and ensure volunteers and volunteer service providers are approaching disability from a rights-based perspective which recognises that disability affects all aspects of daily life.

Thinking in terms of partnerships

Analysis of the qualitative data suggests that a more programmatic and strategic approach to the disability sector would extend and deepen the capacity-building impact of volunteers beyond the individual and community, to institutional and policy levels. A programmatic approach could be developed based on pre-existing assignments and relationships with partner organisations in Australia and host organisations in country, particularly organisations for people with disability, and would have greater capacity to embed inclusiveness in all facets of volunteer assignments. Deliberate and strategic planning that builds upon long-term partnerships, develops linkages between

assignments and institutions and adopts a regional approach that is sensitive to, and supportive of national diversity, is required.

A good programming approach utilises volunteer assignments to strategically develop bridges and links between institutions and organisations. This can be achieved by building on assignments and using the knowledge and experience of one volunteer to plan a mix of further assignments. Serial, multi-sectoral or simultaneous assignments in one sector, such as education or health, and a combination of short and long term assignments are all potential assignment strategies.

The important thing is the logical sequencing of volunteer assignments which evolve over a longer programme timeline with the aim of developing a broad set of skills within the host organisation. Volunteers with complementary skills sets could be placed simultaneously with the objective of building systems, training, programmes and policies. These various strategies need to be carefully designed to meet local needs in a flexible and responsive manner.

The value of a multi-sectoral approach is emerging through in-country experience, for example AVI's work in Fiji, and is consistent with addressing disability as a cross-cutting issue. Planning such a volunteer strategy takes time, as does programme-based recruitment, and current volunteer service providers' one-year funding cycles can be restrictive.

A single regional strategy is unlikely to be the most appropriate way to achieve sustainable outcomes for disabled people's organisations and people with disability in the Pacific. There is no one approach or activity that can be universally applied across such a diverse region without adjusting for local nuances, cultural and institutional differences. Volunteer service providers are advised to support regional forums and organisations for people with disability as they are aware of what works best in particular contexts.

Internal mainstreaming

Volunteer service provider support for disability needs to extend beyond placing volunteers into the disability sector, as the VSO model recognises. Mainstreaming disability inclusion across all volunteer assignments and in volunteer service provider internal and external policies, practices and programmes is required. The equal participation of people with disability as employees and volunteers would bring considerable expertise to volunteer service providers and would acknowledge that disability mainstreaming is an issue of programme content and human resource policy.

Mainstreaming requires an ongoing commitment to inclusive volunteer service provider workplaces, programmes and policies to remove barriers faced by people with disability. In terms of assignments, this means inclusiveness in all areas

and stages of work, from the design of assignments and programmes, recruitment, appropriate briefing and support in country, to debriefing, monitoring and evaluation. In terms of programmes, it means supporting specific disability assignments and incorporating an awareness of and sensitivity to disability-related issues in all assignments, as noted above.

Volunteer service providers have a responsibility to ensure that volunteering is equally accessible to people with disability and that staff are 'disability confident'. To achieve this, targeted recruitment strategies need to be developed and staff, including in-country managers, need to be trained in disability awareness, appropriate rights-based responses across the volunteer cycle, and reasonable accommodation. When volunteer service providers are providing high-quality, individualised support for volunteers, it is likely that the needs of people with disability will automatically be addressed. People with disability generally do not want special treatment; they want to be able to achieve and experience the same things as others.

Informants expressed a preference for volunteer service providers to adopt an inclusive approach to recruitment that is driven from the field. This will increase the availability of potential volunteers who are skilled and suitable, enhance flexibility and strengthen programming potential by providing greater recruitment choices. An inclusive approach is rights-based and requires a barrier-free recruitment and selection process, and trains volunteer service provider staff to be informed and confident in their interactions with people with disability.

Inclusiveness should underpin volunteer positions, but does not mean all positions are appropriate to all. Volunteers may have assignment preferences; for example, some volunteers with children do not want to be in a remote place, while others may not want to live in an urban area. Like all volunteers, people with disability must choose assignments most suitable and desirable to them.

An advocacy approach based on promoting the right of people with disability to make informed decisions regarding volunteer assignments is advised. This requires host organisations providing people with disability with relevant information on the assignment context in terms of accessibility, daily living, transport, social life, cultural attitudes toward people with disability, independence and dependence. Procedures for possible medical emergencies, evacuation procedures and personal safety plans must also be addressed with any particular requirements of people with disability, and possible carers, in mind.

Conclusion

For volunteering to be inclusive, disability must be mainstreamed across the volunteer programme and across internal policies,

procedures and practices. To achieve this, volunteer service providers need to build their capacity to promote a rights-based, inclusive and barrier-free society for people with disability in Australia and the Pacific, as outlined in the BMF. Capacity building is central to the volunteer programme and is defined by AusAID as 'the process of developing competencies and capabilities at the individual, organisation and country level, in ways that will lead to sustained and self-generating performance improvement' (2004:3).

Although capacity-building typically refers to recipient countries, host organisations and volunteer counterparts, it is timely to apply it to volunteer service providers' ability to mainstream disability and to address Australia's obligations under the CRPD. Capacity building in disability mainstreaming needs to occur in all facets of the delivery of the volunteer programme, including the human resource policies and practices of volunteer service providers.

Mainstreaming is fundamentally about removing barriers to the inclusion of people with disability, and the broader goals of empowerment, self-determination and equality of people with disability. There is an inter-relationship between internal organisational values, policies and practices and the effectiveness of external programmatic interventions (Miller and Albert 2005), suggesting that internal and external mainstreaming would ideally occur concurrently. Mainstreaming must aim for sustained change in the lives of people with disability and in the discriminatory attitudes currently preventing equal access. People with disability want rights not charity (see ADB 2005).

The international development community is increasingly recognising that development cannot be successful, nor the Millennium Development Goals achieved, unless disability issues are addressed. Volunteer service providers can model inclusive development practice by adopting a programmatic approach building on the locally identified priorities of disabled people's organisations and people with disability themselves. Listening to the voices of people with disability is the critical first step in an inclusive, rights-based approach to international volunteering.

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Advancing inclusive and culturally sensitive approaches in service support for people with disability: The Australian experience

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Disability supports in New South Wales

Contrary to public perception and despite restrictive immigration policies, a considerable proportion of people with disability in Australia (up to 25 per cent) are from diverse cultural and linguistic backgrounds (Gruhn 2005). The National Ethnic Disability Alliance of Australia (NEDA 2008) estimates that an alarming three out of four people from these communities are missing out on services that are provided for people with disability.

Research investigating the use of health services by individuals aged 16 and above in the state of New South Wales (NSW) across a diverse range of cultural and linguistic backgrounds has found that individuals from non-English speaking/culturally and linguistically diverse (CALD) backgrounds experiencing disability as a consequence of psychological distress were significantly less likely to access health services than those from English speaking backgrounds (Boufous et al 2005). This lack of engagement in support services has been attributed partly to inequity in access, but also to the unsuitable nature of many support services (Carvalho-Mora 2005; MDAA 2002) as well as past negative experiences of service use (Carvalho-Mora 2005).

This paper seeks to briefly address some underlying systemic issues that relate to our failure to engage what has been described by the NSW Multicultural Disability Advocacy Association (MDAA 2002) as one of the most marginalised groups in Australia. The paper proposes that our most challenging obstacles in providing appropriate supports for people with disability from CALD backgrounds emanate from issues that may be seen to exist both nationally and internationally. While the literature refers variously to people from non-English speaking backgrounds or from CALD backgrounds, for the purposes of this paper we include both groups in reference to people from CALD backgrounds.

In the light of Australia's recent ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), this paper argues for the importance of understanding where the needs of people from CALD backgrounds intersect with those of people with disability as separate and combined groups. The paper concludes with some proposals for putting into practice principles of inclusion in order to engage more successfully with diverse groups (also see Griffis, this issue).

Legislative context

As in various parts of the world, a raft of Australian policies and legislation designed to protect the interests of people with disability and people from CALD backgrounds exists. To take some examples from NSW, such policies range from the NSW Charter of Principles for a Culturally Diverse Society (1994), to the NSW Disability Framework (1998), which specifically outlines objectives related to catering for the unique needs of people from a range of socio-cultural and economic groups. Yet there is little evidence of comprehensive service provision geared towards people with disability from CALD backgrounds, with the result that a large proportion of this group are not receiving basic support services (NEDA 2008).

In a summary response to Australia's ratification of the CRPD, AusAID has produced a draft outline of its strategic approach to supporting efforts to improve the quality of life for people with disability. Among AusAID's guiding principles in this work is a commitment to respecting and building understanding of the lived experiences of people from diverse cultural and social backgrounds with disability (AusAID Disability Taskforce 2008). This paper presents a brief summary of some of the major challenges for Australia in working towards this principle.

Myths and misconceptions

MDAA (2002) reports several widely held 'myths' regarding the experiences and beliefs of people with disability who come from diverse cultural and linguistic backgrounds. These include the notions that: that people from diverse cultural backgrounds prefer to 'look after their own' and are therefore less likely to access services; and cultural background is not an issue for people with disability receiving support.

There is growing evidence, in fact, that people with disability are as likely to face discrimination from within their cultural group as they are from wider social groups. Islam (2008) conducted research investigating the perspective of Pakistani and Bangladeshi young people on their negotiated identities and experiences of living with disability:

When I'm going shopping with mum, old people ... old Asian people come over and say have you got eczema. Like they'll just come and ask my mum like I'm not really there and I'm like 'I'm here hello! I'm standing right next to you'.

They just think we, disabled people, are not there, we don't exist (Islam 2008:46).

I got bullied by kids near my house. I think it was because I was different from them. ... I used to go to the local Mosque to learn Arabic. But the Imam kept picking on me cos I couldn't read as fast as the other kids (Islam 2008:48).

The notion that cultural values and practices do not impact on experiences of disability is also widely contested (Ali et al 2001; Garcia et al 2000; Harry 2002; Ingstad and Whyte 1995). MDAA's report (2002) indicates that failure to engage CALD communities in support provision for people with disability is related to systemic limitations in service delivery that reflect a particular set of (Euro-American) perceptions regarding disability and appropriate supports — a notion supported in the research literature (Ali et al 2001; Raghavan and Small 2004). Carvalho-Mora (2005:6) reported that the Disability Council of NSW, in a consultative project, found 'systemic barriers result in multiple disadvantages for people with disability from CALD communities ... As a consequence, to this day people from CALD backgrounds remain under-represented in their access to disability services'.

The problem with 'mainstream' approaches

Policies on provision of support for people with disability in Australia, such as those referred to earlier, do reflect government acknowledgement that cultural factors need to be considered in service delivery but there is little evidence that this rhetoric is widely translated into practice.

Due to an emphasis on preferred 'professional' approaches to providing support for people with disability in NSW, for example, most services offer 'mainstream' services that do not cater for cultural diversity. Only three services in NSW have adopted a 'multicultural' approach, which emphasises the need to respond to individuals' needs in culturally appropriate ways, and three services are adopting an 'ethno-specific' approach, which caters expressly for the needs of a particular cultural group (MDAA 2002).

The problematic aspect of mainstreaming, or 'integration', is 'the implication that somebody who is different is being "fitted in"' (Foreman 2008:13), rather than included as a valued and equal citizen. Inclusion, on the other hand, requires equitable access to enable participation and individual choice. Foreman (2008) identifies a key difference between the notion of mainstreaming or integration and the current move towards inclusion. Mainstreaming involves asking the question '*can* we provide for this individual?' while inclusion moves beyond this to ask 'how *will* we provide for this individual?' (Foreman 2008:14). Inclusion aims to accommodate all individuals

within society, including making adaptations on a practical or social level.

From a societal perspective, the current inclusion movement is attempting to do for those with difference or disability what the women's rights movement, for example, did for women. The movement towards inclusion, with the emphasis on social and practical change to enable valued participation for all, reflects an inherent regard for equality and meeting human rights. It also recognises the need for caution in relation to the potential for negative connotations associated with an emphasis on 'mainstreaming', or 'normalising'. In terms of service provision specifically, inclusion necessarily means working with those with difference and disability to address the question of how to provide support, rather than 'normalising' or requiring conformity to assumed practices.

It is pertinent here to address the concept of 'normalisation' as developed mainly from the writings of Bank-Mikkelsen, Wolfensberger, and Nirje and further developed by Wolfensberger into the concept of 'social role valorization' (cited in Culham and Nind 2003). The concepts of 'normalisation' and 'social role valorization' are based on a belief in the entitlement for all people to live a 'normal' life defined as the lifestyle of the majority of people within a given culture (Foreman 2008).

These concepts have provided food for thought in challenging exclusionary practices and the limitations placed upon choices for individuals with disability. However, inherent within this theory is inferred homogeneity within groups and an emphasis on conformity (Culham and Nind 2003). This leads to failure to recognise the different experiences of people with disability (Ali et al 2001).

Additionally, the concepts of 'normalisation', 'integration' and 'mainstreaming' are problematic in their requirement for the individual to fit within existing systems (Slee 2007), rather than working towards systemic change in order to include all members of society. These systemic issues are evident at various levels, including within support services. However, the current move towards implementation of the CRPD provides a valuable opportunity to challenge these assumptions and work towards breaking down barriers to greater engagement.

Inclusive and culturally sensitive disability support services

When service providers and families 'do not share similar social, cultural, racial/ethnic and/or linguistic backgrounds, discontinuities between their world views may result in cultural conflicts that impede the ability of both groups to work together' (Garcia et al 2000:90). Tomasello (1999) has described humans as unique in their essential need for culture. The particular set of values and beliefs that shapes daily practices across diverse social and cultural contexts forms an essential and necessary

part of life's purpose and meaning. From the food that we eat, to the expectations of and relationships that we have, culture is inherently involved in every aspect of what we do. While it is possible to accept and assimilate other cultural beliefs at some level, changing fundamental ways of thinking and being is far more complex.

A number of issues regarding conventional provision of support for people with disability have been raised, not only with regard to catering for people from diverse cultural backgrounds, but also in terms of their general orientation towards disability. In more recent years the 'disability movement' has championed progress towards a social model of disability, challenging the medical model or dominance of 'professional expertise' (Ali et al 2001). However, conventional disability services have historically been, and often in practice continue to be, dominated by medical and psychological models of human development.

These models have traditionally worked on the basis of 'developmental norms' to diagnose disability and its 'treatment' and assume that human beings develop along a universal trajectory, determined by innate factors. Failure to achieve specified milestones is, hence, indicative of 'impairment'. This approach is in contrast to socially embedded views, including that of Vygotsky, who considered this deficit model unhelpful and instead viewed children as developing within their cultural and biological context (cited in Garcia et al 2000).

As numerous accounts have suggested, medical approaches tend, therefore, to focus on 'curing' physical and mental conditions that do not reflect 'normalised' experiences (Ferguson 2001), with the assumption that a person's medical condition is the cause of their social exclusion (Islam 2008). They also tend to emphasise the need for people to assimilate into society (Williams 2001), rather than on society working to include all. This is likely to be particularly confronting for individuals from CALD backgrounds who, in most Western contexts, already face pressure to assimilate into their communities at various levels.

Inclusion and strengths-based approaches

There is growing evidence of the positive impact of cultural values on outcomes for people with disability from diverse backgrounds. For example, in relation to parenting, Skinner et al (1999) found that Latino mothers belonging to the Catholic faith tended to highlight the positive impacts of having a child with disability, related to their feelings of becoming virtuous through being 'good' mothers to their children.

These mothers' narrative accounts focused more on the process of adjustment and personal growth than on coming to terms with the implications of their child's impairments, as would be expected based on the dominant psychoanalytic perspective on parental responses to having a child with disability (Ferguson 2001).

Hussain (2005) outlines the complex nature in which culture can shape experiences of disability, both negatively and positively. She also indicates that the impact of these values differs across groups and shapes the experiences of people with and without disability.

Blacher and Baker (2007) explored the positive impact for families of having a child with an intellectual disability, finding positive impact across the sample, but higher levels of positive impact for Latino parents as compared to Anglo parents. Importantly, the research in this area has found that a child's challenging behaviour impacted more negatively on parental wellbeing than the presence of a disability (Blacher and Baker 2007), indicating that cultural differences intersect with a range of factors and may be differential across aspects of disability and across groups.

Such examples highlight the inherent and potentially positive role of cultural values and beliefs in coping strategies and expectations of those who are affected by disability. They also serve as a valuable reminder that the widely held assumption that information and knowledge provided by 'experts' is more credible and preferable to the knowledge of clients, or parents (Ferguson 2001) needs to be actively challenged. As Patterson and Blum (1993) indicate, this assumption extends with all the more inference to people from CALD backgrounds, as knowledge of cultural practices related to chronic illness has tended to focus on exotic beliefs that contrast with Western 'expertise' and often perpetuate cultural stereotypes of 'backwardness'.

Individual needs are complex and situated within diverse social contexts. Although we have focused here on the unique experiences/characteristics of people from CALD backgrounds, the notion that values, beliefs and experiences need to be acknowledged applies to all people for whom support services are provided. In order to facilitate greater engagement in services, it is therefore important to appreciate these individual differences and experiences.

From this viewpoint a more inclusive approach to service provision becomes possible. The social model of disability incorporates social attitudes and systems as major factors in experiences of disability. This paper proposes that the principles underlying the inclusion movement are key to moving forward in overcoming barriers to engagement in support services. It is within this approach that the issues faced by CALD minorities and people with disability, as separate and combined groups, might fully intersect. Being inclusive in our approach to service provision may facilitate greater and more equitable access to services for all members of society.

Table 1 provides examples of practical steps that can be taken to ensure that individuals' beliefs and practices, whatever their

Table 1: Summary of strategies for culturally-responsive support provision, based on principles of inclusion

Study	Challenges	Strategy
<p>Semi-structured group interview of occupational therapists working with people with intellectual disability from culturally diverse backgrounds (Francisco and Carlson 2002)</p>	<p>Ethnocentric service provision</p> <p>Barriers attributed to clients (i.e. reluctance to communicate)</p> <p>Difficulties in engaging clients</p>	<p>Therapists need to develop awareness of their own cultural values and beliefs.</p> <p>Offer interpretation services — even when clients speak English, they may not feel comfortable communicating in a ‘foreign’ language.</p> <p>Consider different forms of communication: face-to-face communication may be preferred to telephone conversations.</p> <p>Consider involving the community in therapy programmes: incorporate celebration of cultural holidays/events in planned activities.</p> <p>Consider influence of cultural values on clients’ beliefs and practices.</p> <p>Are children expected to be independent from an early age (or not)? What skills are valued by family and community members (verbal language, motor skills)?</p> <p>Is there strong family/community support and involvement? In some cultures, involvement of family members is critical.</p>
<p>Review of national and international research into cultural competence in disability support services (Harris 2004)</p>	<p>Engaging clients from diverse ethnic backgrounds</p> <p>Responding to unexpected challenges</p> <p>Developing successful relationships</p>	<p>Research ethnic community services in local area.</p> <p>Distribute information regarding disability service to local ethnic community and vice versa.</p> <p>Facilitate cooperation between relevant agencies.</p> <p>Consult local ethnic community leaders and community workers.</p> <p>Obtain local community profile information (from local council and other organisations in the area).</p> <p>Avoid cultural stereotyping (e.g. assuming that all families from Asian cultural backgrounds will be close-knit and supportive).</p> <p>Actively interpret and analyse challenging situations — are alternative approaches available? What assumptions are being made about a client’s needs?</p> <p>Establish trust and mutual respect through development of shared goals and expectations, sensitive communications, shared evaluation of outcomes.</p>

cultural or social background, are valued and utilised to create appropriate, responsive supports that are likely to engage and benefit both client and provider.

Recognising the need for inclusion on the basis of both disability and culture seems to be an important issue to

consider in relation to the implementation of the CRPD. Addressing the range of needs that exist across diverse groups in our society through inclusive support provision represents a step forward in achieving the internationally recognised goal of equality.

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Addressing disability in Indigenous communities: The Australian situation

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Indigenous people with disability can face multiple barriers to their meaningful participation within their own communities, as well as within the wider community. They often face the double disadvantage of discrimination based both on their Indigenous identity as well as their disability. The voices of many Indigenous people with disability remain largely unheard.

Throughout Indigenous communities in Canada, New Zealand and Australia the prevalence of disability is generally accepted to be twice the rate of the non-Indigenous communities. This paper focuses on the lived experience of Indigenous Australians.

Disability in Indigenous Australia

A 2005 report of the Commonwealth Steering Committee for the Review of Government Service Provision (2005:3.6) found:

The proportion of the indigenous population 15 years and over, reporting a disability or long-term health condition was 37 per cent (102,900 people). The proportions were similar in remote and non-remote areas. This measure of disability does not specifically include people with a psychological disability.

The high prevalence of disability, approximately twice that of the non-Indigenous population, occurs in Indigenous communities for a range of social reasons, including poor health care, poor nutrition, exposure to violence and psychological trauma. These situations can arise from removal from family and community and substance abuse, as well as the breakdown of traditional community structures in some areas. The report shows that Indigenous people with disability are significantly over-represented among homeless people, in the criminal and juvenile justice systems and in the care and protection system (both as parents and children) (ibid).

Medicalisation of disability services

Historically much of the focus on Indigenous Australians with disability has been from a health perspective. While this is essential, particularly regarding primary health interventions, it has come at the cost of failing to recognise the social aspects of Indigenous disability. Thus the barriers that produce discrimination against Indigenous people with disability remain

firmly entrenched and the general wellbeing of Indigenous people with disability has not improved in any meaningful way.

The experience of many Indigenous Australians with disability is that their disability is medicalised with interventions simply treating the individual's health condition without considering the broader implications of their condition, i.e. the social barriers to participation. This is an ongoing problem as significant funds are directed into Indigenous health programmes without the foresight to consider the broader social needs of Indigenous Australians with disability.

An example of how this manifests relates to an elder who presents to a hospital with complications related to his diabetes. As a result he has to have an amputation. After he has recovered he is simply wheeled out the front of the hospital without any ongoing supports being provided. He returns to an inaccessible home and an inaccessible community. While he has had a medical intervention there has been no positive intervention to ensure that he maintains not only a quality of life but his dignity.

Another example where disability is overlooked in Indigenous communities relates to the problem of otitis media (glue ear) that has a high prevalence in some Indigenous communities. Today there are simple positive interventions that mean Indigenous children are completely treated for glue ear but there are no programmes addressing the acquired learning disability that many Indigenous children have acquired because their problem was not treated quickly enough.

Other social issues

The impact of colonisation and the resultant dispossession of land and displacement from places of cultural significance have had an impact on the lives of many Indigenous people with disability which is difficult to measure. Invasion and colonisation can be directly attributed as causal factors of disability among Indigenous communities particularly in the area of mental health. This is further compounded by the fact that the non-Indigenous mental health sector does not know how to effectively support Indigenous Australians with mental health needs that relate to dispossession and colonisation.

In Australia today there are very few Indigenous people with disability who have their needs met in any significant way. The vast majority do not receive any support other than that provided by their immediate family or through kinship networks which themselves invariably have unmet needs of their own.

Indigenous people with disability are significantly under-represented as participants in beneficial social programmes (including health, community and disability services) due to a number of policy and structural failures. These include services that are poorly targeted and located, as well as culturally insensitive or inappropriate. Furthermore, there are very few Indigenous-specific disability services, or non-Indigenous disability services with Indigenous staff.

In many cases, particularly in rural and remote communities, Indigenous people with disability are the victims of institutional racism that often results in little or no service provision. Today, sadly, this remains a major barrier for Indigenous people with disability in their desire to be able to meaningfully participate in the wider community.

Conclusion

There is much to be done to promote and protect the human rights of Indigenous people with disability. In Australia there is an urgent need for greater support and resources to assist in the development of a social movement of Indigenous people with disability. It is critical that Indigenous people with disability themselves lead the agenda so that they can effectively advocate for change not only in the wider community but also within the Indigenous rights movement in Australia.

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Reference

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Can we use the values and community orientation of community-based rehabilitation in its evidence base?

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Many people recognise that it is important for community-based rehabilitation (CBR) and disability services in developing countries to build a stronger evidence base. They realise that better and more evidence will help to improve CBR practices, and that this will lead to better disability services. Most importantly they emphasise that it will lead to better outcomes for people with disability and their families and communities. While we agree this is vital, we also suggest that there are a few ways of thinking about evidence, and there are some things we should keep in mind as we seek to establish a better evidence foundation for CBR. First, we should remember the unique values of CBR and incorporate them into our evidence base and second, we need to include research from a community perspective. These aspects are sometimes forgotten, but we think they're important.

Incorporating CBR model values

CBR has evolved a lot over the decades (see Kuipers 1998). As a dynamic approach with multiple layers and different strategies, it can and does respond to diverse political, cultural and social contexts and different organisational and financial factors. Therefore the sort of evidence that should inform CBR should also be broad, comprising a mix of principles and values as well as relevant research findings. In light of new understandings of evidence, which include values (Sackett et al 2000) and philosophies, we suggest that decisions about the CBR approach should be informed by values as well as traditional research, and that these values should be acknowledged and actively debated. For example, some CBR values are outlined below.

Originally CBR was an attempt to meet the need for adequate and appropriate rehabilitation and disability services for all people in developing countries. CBR then, like other rehabilitation models, is based on an understanding of the value of *rights and worth* of all individuals (Helander 1993). Recognising the disadvantage experienced by most people with disability, many CBR initiatives seek to enhance their rights and roles in society. *Social empowerment* of people with disability, family members and communities is a key value inherent in CBR (Kendall et al 2000). Again, this value is shared to varying degrees by many rehabilitation models.

The CBR model is a bit different from some other models because of its focus on the community. Where possible, the CBR

approach seeks to utilise and build on existing resources, and involve people with disability, their families and communities. So, CBR programmes aim to be *context-specific*, influenced by social and other factors within the community (Kim and Jo 2001). They provide rehabilitation, training and vocational opportunities and seek to improve the integration of people with disability into their local communities. The ideal for effective CBR programmes is that people with disability, their families, the community, community workers and health professionals collaborate to provide services *recognising the value of the local community* (Mitchell 2001).

Another value that can be seen in the CBR model is *community participation*. This results in greater involvement of family members and local volunteers in the rehabilitation process (Boyce et al 2002), and less travel and expense for people with disability. When this value influences services, family and community members can see the gains people with disability are making, and they can continue to participate in the social, cultural and work life of their community. The value of community participation is also linked to two other values key to CBR. First, *cultural appropriateness* — employing local people is more likely to result in culturally appropriate practice (eg. language, religion), and lead to the use of locally-available materials. Second, *cost effectiveness* — the use of family and community volunteers reduces the dependence on external professionals, which decreases service costs and promotes sustainability.

The focus of CBR programmes is usually to support all people with disability across a community (horizontally), rather than focusing vertically on a specific group or those with a particular disabling condition. This distinction highlights an important values issue that informs choice of model. For example, in the case of working with people with leprosy, practitioners who hold a community-oriented values framework, argue for the integration of leprosy treatments and control programmes into CBR and similar horizontal approaches (Deepak 2003). They express the position that a key to combating social stigma is social and service integration (Frist 2000). Others who emphasise the values of specialised services prefer a traditional vertical service model for the same reason, to prevent the social stigma people may experience (Seddon and Seeley 2006; Arole et al 2002). This highlights our suggestion that at the level of

model, values need to be made explicit and debated and then incorporated (along with research) into the evidence debate and decision making.

Reflecting these values in research

We think that a dimension currently under-recognised in the evidence debate, is that of the voice of people with disability, their family members and communities. Given the CBR focus (at the local, community level), maybe we should also seek new forms of research that are responsive to service-users (ie, listening to people) as a foundation for evidence. The new UN Convention on the Rights of Persons with Disabilities (UN 2006) enshrines people with disability's 'full and effective participation and inclusion in society' as one of its general principles. This should include developing appropriate ways of ensuring that people with disability can participate in research which will shape the evidence base for future services.

Across CBR more broadly, there are increasing efforts to ensure that the voices of people with disability are heard, at both the individual level and at the collective level. At the individual level, CBR is increasingly adopting the 'social model' which acknowledges the influence of social factors on people with disability's functioning and requires their active participation at all levels. At the collective level, an increasingly rights-based approach to CBR is giving disabled people's organisations (DPOs) a larger role in the initiation, implementation and evaluation of CBR programmes (ILO, UNESCO and WHO 2004). CBR practitioners should therefore collect evidence through participatory methodologies at both of these levels.

In CBR, approaches such as participatory rural appraisal (PRA) are particularly suited to gathering evidence from people with disability and communities in CBR programmes. PRA may be described as a toolbox of research *methods* which are appropriate for communities with low levels of education and little research experience, (eg, visual and oral methods and use of local materials which allow everyone in the community to participate). However, more importantly, PRA is a *philosophy* by which outside researchers learn from communities and encourage them to take control of the research process. In so doing they can provide information from their perspective which informs CBR service delivery. The challenge is to turn this information into evidence for practice.

While PRA is now commonly used in community development, there are added challenges when used in the area of disability and development. First of all, disability is rarely if ever a priority issue for communities, so before collecting evidence from communities on disability there is need for community sensitisation to disability issues. Definitions of 'disability' vary across cultures, and hidden and mild disabilities may not be recognised. Communities may only raise a narrow range of disability-related issues, such as loss of

income, and not be aware of other issues such as the psychosocial effects of disability, communication problems or problems facing women with disability.

There are also a number of other challenges in carrying out PRA activities with people with disability themselves, since they are often the poorest, most marginalised people in the community. Their marginalisation can exclude them from participatory processes in a number of ways: due to extreme poverty (being unable to participate due to more pressing economic needs); by being ignored or considered unimportant by more powerful people in the community; through communication problems (eg, for people with hearing or learning difficulties); mobility problems; or by being unaccustomed to forming or expressing their opinions.

At the collective level, evidence on CBR programmes can also be gained from people with disability acting through their DPOs. In some countries, DPOs have informed national policy debates on poverty reduction and debt alleviation (Dube 2005), however this may be a long-term aspiration for many others. In places where DPOs are relatively newly-established and have limited resources and capacity, genuine representation across gender, disability type, children's issues and rural/urban issues is more limited.

Developing participatory methodologies to gain evidence

How then do CBR programmes go about ensuring community and people with disability's participation in collecting evidence? A CBR organisation in Cambodia, Disability Development Services Pursat, piloted methods of enabling illiterate, inexperienced rural people with disability to lead participatory exercises to plan CBR activities (Harknett et al 2005). The research team of rural people with disability were trained in a range of PRA exercises (mapping, ranking, role play, household surveys, Venn diagrams, etc) and carried out surveys of people with disability and their communities in three villages. Many of the lessons learned on participation in planning CBR are also applicable to gathering evidence during a CBR project to inform practice and service delivery.

The research team identified people with disability across the region, using a set of picture cards depicting types of disability to ask villagers how many people in each category of disability there were in the village, and explore incidence of disability. They also identified people with disability's main concerns and potential project priorities through focus group discussions and individual ranking (using a number of stones to rank importance). This method could also be used to gather evidence on the effectiveness of CBR interventions, or to compare questions of different methods of service delivery, such as service uptake and service effectiveness.

At the collective level of people with disability's participation, CBR programmers should also make efforts to include DPOs in gathering evidence on CBR. While DPOs are weak in many countries, it should be realised that they have 'the right and the responsibility to identify the needs of all people with disability, to make their needs known and to promote appropriate measures to address their needs' (ILO, UNESCO and WHO 2004). This is the sort of evidence that CBR services should seek, to inform service delivery.

Limitations in participatory methods

Clearly there are limitations to participatory research done by village people with disability. Lack of numeracy skills necessitate additional support. Low status and poor self-esteem (especially of women with disability) make leadership of activities problematic, and limited community development skills may inhibit the generation of village-based solutions. Further, some aspects of research such as the measurement of outcomes usually rely on specific rehabilitation skills and understanding, and may be difficult for people with disability and community members without substantial support. Despite these limitations, we suggest that a commitment to 'hearing' the voice of people with disability and community members will result in an important source of evidence for CBR.

Similarly, there is considerable scope for bias from data collected by community members (either exaggerating positive effects of a project or intervention to please others, or over-emphasising difficulties in order to persuade the project to continue). While such bias may occur in data collected by organisations and DPOs, it may be particularly evident in any project working with vulnerable and marginalised people.

Due to these potential sources of bias, CBR programmes should always cross-check participatory data gained via people with disability and communities. This cross-checking, or triangulation (Gosling 1995), might take place through: collecting data with a multi-disciplinary team using visual, verbal, group and individual methods, and through using a range of different sources of information (men, women, children, people with different types of disability, with different levels of exposure to the CBR project), with different connections to the CBR project.

Conclusion

After nearly 30 years of experience worldwide, CBR is still struggling to gain recognition as a legitimate model of service provision to people with disability. An important step in this process will be the development of a broad evidence base. We think that using the evidence from rehabilitation services in economically developed countries may be promising for informing CBR rehabilitation techniques. We also think

synthesising CBR evaluation reports will give us useful evidence. In this paper we've stressed that there is a need to better understand and incorporate CBR's 'values base' into its 'evidence base'. In keeping with underlying values in CBR, we suggest that CBR needs some creative new methodologies for determining evidence. These methods should emphasise participation at the community level, they should include the service users themselves, their advocates in DPOs, and local community members. Appropriate research methods, drawn from the experience of the wider community development field, should be used to make sure the voice of village people with disability is heard and incorporated into a unique, multifaceted evidence base for the discipline of CBR (also see Wiley and Lowry, this issue).

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Putting disability on the aid agenda: The Australian Disability and Development Consortium

Paul Deany, Coordinator, Australian Disability and Development Consortium

The Australian Disability and Development Consortium (ADDC) is an Asia-Pacific network focusing attention, expertise and action on disability in developing countries. It was developed in response to the estimated 650 million people with disability. Two thirds or almost half a billion of these live in Asia. Among the poorest of the poor, they are the world's largest minority (UN nd).

The ADDC was launched at Parliament House Canberra in early 2007 and this fledgling network has already helped to put disability firmly on Australia's development agenda. There is now strong political and bureaucratic commitment to disability. The evidence for this includes the new AusAID strategy, *Development for all: Towards a disability inclusive Australian aid program for 2009-2014*.

This commitment from Government mirrors the growing recognition in the broader disability and development sectors that disability is a fundamental cause and a consequence of poverty. The ADDC has been a central player in these recent developments. Anecdotal and other evidence indicates that this network's formation and advocacy work was pivotal in this national shift on disability and poverty, demonstrating the value of advocacy networks in policy development.

Beginnings

The ADDC grew from the Disabilities and Development Working Group instigated by international development agency, CBM Australia, for the Australian Council for International Development (ACFID). The working group started in 2002 and by 2005 had over 50 members. But a growing interest outside the development sector from universities, individuals, disability services and others led to the formation of a larger national and now regional network. ADDC membership has grown to over 350 individuals and agencies representing a number of disability, development and academic agencies.

During 2007-2008, key activities for the network included:

- establishing the ADDC secretariat at CBM Australia;
- consulting and working with disabled person's organisations (DPOs) and people with disability from the Pacific and Asia;
- managing the ADDC via its Advisory and Executive Committees which include DPOs, people with disability and representatives from the aid and disability sectors;
- establishing a members' database and electronic discussion forum with regular updates and information exchange;
- the ADDC website: www.addc.org.au;
- staging the Access for All photo exhibition around Australia;
- seminars and training workshops in Sydney, Canberra and Melbourne;
- working with major Australian political parties on disability and development;
- hosting with Australian National University and ACFID, *The First International Conference on Disability, Disadvantage in the Pacific and Asia* on September 29-30 2008 for 220 participants;

- hosting with the Australian National University and ACFID a one day *Disability and Development Policy Roundtable*, October 1, 2008 for 90 largely international participations; and
- acting as a key reference group for the Australian Government and AusAID on disability and development.

Lobbying successes

Of all these activities, work with Government and the Coalition on disability in Australia's aid programme has seen significant policy shifts and a commitment to disability as a key aid issue.

A number of factors led to this:

- involvement of people with disability and DPOs from the outset;
- strong response from politicians to the ADDC and the issue of disability;
- close collaboration and consultation with AusAID;
- sustained advocacy by CBM Australia on disability and Vision 2020 Australia on the right to sight;
- support from ACFID, National Disability Services and other key ADDC members;
- a very active, representative and involved ADDC core group, steering this nascent network;
- ADDC members and others being vocal on disability as a neglected issue in our aid programme and;
- the UN Convention on the Rights of Persons with Disabilities
- being signed and ratified by a growing number of countries, with Australia one of the first Western countries to do so.

The future

As Australia's and now the region's largest network of agencies working on disability in developing countries, the ADDC is in a unique position to lead responses on disability. Rather than being an implementer of disability programmes itself, ADDC is a network which includes a wide range of agencies and practitioners with extensive experience in disability and development.

As such, the ADDC is a key reference group for its members as well as the Government and AusAID as they implement their strategy for a disability-inclusive aid programme.

In practice, this means the ADDC is:

- a communication and coordination point for the disability and development sectors through its membership;
- a link between Australian and partner agencies in developing countries;
- setting an agenda for disability inclusion in Australian aid activities, ensuring that the highest standards of human rights, evidence-based practice and sustainable development inform all Australia's overseas disability work;
- developing mechanisms for promoting ownership, inclusion and partnership with people with disability and DPOs;
- a key technical resource to AusAID and Government as frameworks and priorities for action on disability are developed and;
- a link to International Disability Networks including the International Disability and Development Consortium (IDDC), World Bank Global Program on Disability and Development (GPDD), and similar coalitions in Europe and North America.

Conclusion

The ADDC has demonstrated that coordinated, vocal advocacy can unify fragmented national interest on disability in developing countries and help foment strong national action. Much more work remains, but the early indicators are that the ADDC is an important and necessary vehicle for Australia's international work on disability issues.

ADDC membership is open to individuals, agencies and peak bodies. For further information contact:

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Disability and development in Thailand: A case study of a partnership with South Australia

Margaret Gadd, Asia Pacific Partnerships, National Disability Services

Much rhetoric exists about 'partnering' in the international development community today. While this term appears to reflect a variety of meanings and forms, it is clear that the basis of many relationships between governments, regional organisations, business, civil society and the research community has shifted from a donor-driven supply model to a more collaborative approach which requires shared goals, mutual respect and two-way interaction.

Partnerships in development are increasingly being encouraged. For example, the draft Disability Strategy for the Australian Aid Program 2009-2014 includes as one of its guiding principles: 'We will actively promote and support people-to-people links and partnerships' (AusAID 2008:10). The Strategy also seeks to contribute to leadership on disability and development by identifying opportunities to 'build strategic partnerships through which Australia can support and strengthen efforts of international and other potentially influential partners' (ibid:19).

However, despite an apparent consensus on the value of partnering, there is still a view that need exists for more research and evidence of effectiveness in this area. References to, and support for, partnerships abound in material on the websites of most international development agencies, but practical guidelines for implementation and/or evaluation are difficult to find.

It appears to be the case that 'the international development system still provides little to no real guidance on *how* to equitably create and function in a partnership, or how to *evaluate* the effectiveness of this approach to capacity-building' (ALPI 2006:6). Sharek et al (2007) also claim that partnerships can facilitate effective implementation of best practices, but literature describing effective strategies to address barriers to implementation is lacking.

The following case study of a six-year partnership between the disability sectors in Thailand and South Australia may offer some guidance to other organisations committed to moving beyond donor-recipient relationships towards relationships based on shared goals, mutual respect, ongoing dialogue and collaboration.

The partnership

Since 2002, non-government service providers and counterpart government departments in Thailand and South Australia have worked together to achieve improved outcomes in the lives

of people with disability in Thailand. Over the past six years, stakeholders in the partnership have included people with disability and their families, NGOs, and staff and management of the Thai Department of Social Welfare and Development (DSDW) and the South Australian Department for Families and Communities (DFC). Funding support has been provided for specific projects by AusAID and Australian Business Volunteers.

In 2002, a social worker with the Foundation for Children with Disabilities in Bangkok (FCD) emailed the President of the Australian Cerebral Palsy Association (ACPA) seeking assistance for families of children with disability to attend a conference in Adelaide.

Unfortunately, it was not possible to meet this request directly, but the email raised much interest.

The ACPA President was also the Chief Executive Officer of Community Accommodation and Respite Agency (CARA), a service for people with severe and multiple disabilities in Adelaide. With a commitment to sharing knowledge and expertise with other agencies, and having staff with experience in overseas development activities, CARA asked for more information about FCD's work and the needs of the people they supported.

CARA learned that, despite Thailand's emergence as a rapidly developing and progressive country, significant challenges remained for people with disability and their families. Many children born with disability are abandoned, and many thousands of people are still living their entire lives in large government institutions as a result of poverty, lack of support services and social stigma.

FCD aims to support new parents of children with special needs to develop the skills and understanding to care for their child at home. In its 20-plus years of operation, FCD had been able to assist a large number of families through centre-based and outreach services in Bangkok and some rural areas. However, they recognised the potential benefits of communication with CARA and asked specifically for guidance in understanding 'respite', and support in developing culturally-appropriate respite services for Thai families.

Growth of the partnership

In 2003, CARA and FCD applied jointly to AusAID for assistance through the Community and Professional

Development scheme, and received a small grant of \$18,720 to develop a respite service model in Thailand. A key factor in the success of the grant application was that dialogue and friendship had already been established between the two agencies.

With careful management of funds and regular email communication, ten exchange visits occurred during 2003-2004 for the facilitation of planning workshops, training, implementation and observation. Representatives of the FCD Board, staff and parents visited South Australia, while one CARA Board member and five staff visited Bangkok.

Many other people from both countries were involved in arranging the exchange visits, resulting in the development of strong bonds between the two organisations.

As an adjunct to the primary project, CARA also delivered a comprehensive 'Train the Trainer' programme for the nursing team at a major rehabilitation hospital in Bangkok. This enabled the hospital to train non-medical people (NGO staff and families) in essential aspects of disability health care into the future. Australian Business Volunteers (ABV) provided funding for this project. (see also Hill, this issue)

Early challenges

As in any relationship, some differences in levels of understanding and expectations became evident, particularly between the FCD Board, staff and families.

Board members initially expected that all communication and planning would be conducted directly between CARA and FCD Board members, while the inclusive approach preferred by CARA, and day-to-day project functioning, necessitated direct liaison with staff and families. Despite the strongly-worded FCD philosophy of parent empowerment, some Board members found difficulty in accepting that parents had the skills and confidence to move forward and work independently in their own communities.

These challenges were overcome with time, patience, mutual respect and active communication among all parties. Exchange visits assisted in demonstrating that the evolution of strengths within FCD mirrored the experience of Australia and other western countries; for example, the growth and effectiveness of peer-support disability organisations and parent advocacy groups, and the movement away from hospital and institutional services to community-based services.

Frequent clarification of roles and concepts and involvement of all stakeholders assisted in achieving major steps towards change and development.

Ongoing challenges include strengthening the capacity of in-country resources to meet the needs of children with disability and their families. Some of the Thai people involved in various stages of the partnership were initially sceptical that it would be possible to recruit and train fellow country people who had

had no previous experience of disability, despite learning and observing that disability support services have evolved over time in Australia.

The next stage of the partnership helped significantly in addressing some of these challenges.

Government partnership

An important step forward involved CARA and FCD facilitating links between government authorities in Thailand and South Australia. Based on the initiatives already undertaken by the NGOs, senior executives from government departments in both countries supported the idea of sharing expertise in research, policy development, establishment of service standards, de-institutionalisation and development of community-based models of service delivery.

In 2005, the Thai government funded a South Australian visit for a group of senior executives and managers of Thailand's Department for Social Development and Welfare (DSDW) to meet with representatives of the South Australian Department for Families and Communities (DFC), and observe community-based disability services.

This visit led to an AusAID grant through the Public Sector Linkages Program for a three-week training program in Adelaide for 13 staff and therapists from Thai Government disability services and institutions. And for a follow-up visit by the South Australian training team to support the implementation of projects planned during the initial training programme. Following the success of this programme and the strength of the partnership, the Deputy Director General and senior staff of DSDW visited South Australia and Canberra in 2008 to report on progress to the Department for Families and Communities and to AusAID.

Partnership outcomes

Between 2002 and 2008, the following major outcomes have been achieved:

- The concept of 'respite' has been introduced, and models of service provision have been established in Thailand. Centre-based respite programmes commenced at FCD in mid-2004 with 'volunteer' parents caring for each other's children overnight or for a few hours during weekends. There is no word for respite in the Thai language, but the concept of a quality alternative to family care has been embraced by all involved in the partnership over the past six years.
- The capacity and self-esteem of parents/families has been enhanced to the extent that, since 2005, two self-managed parents groups have evolved from the original FCD peer-support programme. These groups now receive funding from the

Thai Government and the local business sector. Replication of this model of peer support is being encouraged by DSDW in other parts of Thailand. The groups provide early intervention support and advice, education, family day care, outings, holiday camps and other activities as forms of respite and recreation.

- Parents, NGO staff and health professionals in Thailand have gained skills and knowledge related to the health care needs of children with severe disability. DSDW is developing policies on deinstitutionalisation and community-based disability services in Thailand. Pilot accommodation and respite programmes are being implemented, following the training and support provided by the South Australian Department for Families and Communities. Significant learning and cultural exchange opportunities have been gained and valued by Government and NGO employees in South Australia.

It is difficult to quantify the extent to which the parents' groups and pilot community accommodation programmes are assisting in breaking down barriers to discrimination and stigma, but there is clear evidence of greater community inclusion for the children and families who participate in the groups. With the support of DSDW and local businesses and communities, and the replication of similar models across Thailand, there is strong reason to believe that the rights of people with disability will increasingly be recognised in Thailand.

Evaluation of principles for success

The Thai/South Australian partnership has grown and strengthened over a six-year period without the benefit of any initial clearly planned framework for evaluation (beyond AusAID reporting requirements). However, a post-hoc review has identified the following key factors which have been critical to its success and sustainability:

- a common vision and commitment to improved outcomes for people with disability;
- mutual respect and regular communication;
- involvement of as many people as possible — particularly people with disability, families, service providers and government personnel;
- support of key people in both countries (board members, management committees, senior executives);
- a 'driver' in each country to lead, guide and encourage — as with any approach to development, partnerships require sound management;
- patience and willingness to continue when challenges arise;
- extension of the networks by including other organisations and individuals in each country;
- taking time for reflection and seeing the 'big picture'; and
- enjoying the achievements, celebrating and valuing the friendships.

Comparison of the above list against a list of guiding principles identified by Horton et al (2003:74) finds that the

Table 1: Elements for success in capacity-building partnerships

Link to organisation's mission, strategy and values	A partnership should contribute to each organisation's mission and be consistent with its strategies and values.
Clear purpose and intent	Each organisation should determine why the partnership is useful to the achievement of its goals. Discussing the purpose up-front is important, as incorrect assumptions may lead to later disagreements and conflicts.
Clear division of roles and responsibilities	Each organisation needs to take responsibility for its own development. In capacity development, the partners need to play different roles and perform different tasks. Power imbalances in international partnerships make it especially important to negotiate and define roles and responsibilities.
Principled negotiation and joint decision-making	Principles should be established for the relationship prior to action. Ownership is promoted when all parties are actively involved in decision making.
Openness in learning and change	Learning is at the heart of capacity development, and it needs to take place in all participating organisations, not just in the 'beneficiary' organisation. In an environment of mutual trust, monitoring and evaluation can promote learning.
Continuity and persistence	Capacity development is a process which requires time, resources and persistence. While persistence does not guarantee progress, it has a high payoff in most capacity development efforts.
Flexibility	Relationships need to change over time as conditions and issues evolve. All partnerships end at some point and plans for phasing out should be anticipated.

practical experience of the Thai/South Australian partnership largely mirrors the findings of broader research — see Table 1.

It is worth noting that a key point raised under the heading of ‘clear division of roles and responsibilities’ is the issue of balance, or imbalance, of power in international relationships. It is obvious that if one party has more resources (for example, funds), or control over these resources, there is a high chance of the relationship operating in a donor-recipient mode, regardless of rhetoric and genuine intent to work as partners.

It is fair to say that this important issue was not recognised or initially discussed between NGO or Government stakeholders in Thailand and South Australia. However, if power refers to the ability to act freely, make decisions and share leadership, then it is probably also fair to call the Thai/SA relationship a true partnership. Only an external review could objectively assess the balance of power-sharing and leadership in this partnership, which again reinforces the need for further research and development of evidence-based guidelines for practice and evaluation frameworks.

Conclusion

The partnership between the disability sectors of Thailand and South Australia provides an example of how ‘from little things, big things grow’. Partnerships can start in a small way and evolve over time to achieve worthwhile outcomes for all stakeholders.

With shared values, mutual respect, common goals and inclusive rights-based practice, the collective action of individuals, service providers, governments and civil society can bring about sustainable change and development.

However, more focused research and evaluation of ‘partnerships’ as a disability development model would add value and greater guidance to the international development community and more effectively ensure the achievement of outcomes being sought by and for people with disability in the developing world.

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Fiji Disabled Peoples' Association's human rights project: A case study

Angeline Chand, *Pacific Disability Forum*

This case study provides an overview of a human rights project undertaken by the Fiji Disabled Peoples' Association (FDPA).

Background

FDPA was established in the early 1970s by a group of people with disability participating in sports. International exposure gained from sporting trips led the group to form an association to advocate for the rights of people with physical disability.

In the early 1980s, FDPA changed its focus from physical disability to become an umbrella organisation promoting human rights and equal participation of people with disability in all areas of life. FDPA has three branches around Fiji as well as a women and youth committee. It also has four affiliated organisations which advocate for these groups: Fiji Association of the Deaf, Psychiatric Survivors Association, Spinal Injuries Association, and United Blind Persons of Fiji.

In 2005, FDPA was awarded an Australian Government small grants scheme based on a proposal to undertake a human rights project for people with disability.

Outcomes

With this small grant, FDPA produced a number of resources under the slogan 'Human Rights are Everyone's Rights'.

A key resource produced was *People with Disabilities and the Bill of Rights — A Guide to Chapter 4 of the Constitution of the Republic of the Fiji Islands*. The content was generated by five people with disability (three women and two men) who examined Sections 25–39 of Fiji's Bill of Rights.

Another publication generated was *Know Your Rights — A Guide For Persons With Disabilities*. This resource aims to educate and empower people with disability by informing them of their rights and steps they can take if they feel their rights have been violated. Areas covered include: access to information and communication technology, and to public places; freedom from cruel and degrading treatment; education and training; and lodging a complaint.

Other resources and booklets have been translated in Fijian and Hindi, and made into audio tapes, braille, DVD, and video.

The human rights project and awareness programme has also contributed to:

- Fiji rectifying the ILO Convention 159 on vocational Rehabilitation and Employment (Disabled Persons);
- wider awareness of the Biwako Millennium Framework (BMF) and the establishment of a BMF committee, including coverage on Fiji Television;
- the placement of a sign language interpreter for deaf students in two Suva secondary schools;
- an increase in the number of trained sign language interpreters in Fiji;
- the publishing of Fiji's sign language dictionary;
- the opening of Qarase House, the Fiji National Council for Disabled Persons headquarters, housing nine disability organisations;
- the founding of the Psychiatric Survivors Association of Fiji;
- greater public awareness on mental health and mental illness issues;
- a 50 per cent subsidy on bus fares for people with disability;
- Fiji currency notes printed in different sizes, making it easier for people with disability to recognise different notes;
- an increase in employment of people with disability;
- Fiji's draft disability policy;
- questions on disability being introduced into the 2007 Census;
- access features appearing in new public buildings; and
- wider community awareness on issues relating to disability.

FDPA and its affiliated groups were also presented with three Pacific Regional Rights Resource Team Pacific Human Rights Awards (a Secretariat of the Pacific Community programme) in recognition of:

1. demonstrating exemplary initiatives and advancing the human rights of persons with disability, and outstanding work in empowering people with disability in decision making;
2. strong commitment to fighting discrimination and asserting the rights of people with disability in employment; and

3. strong commitment and a sustained approach towards promoting social justice and human rights of people with disability.

Conclusion

Although disability issues have come a long way in Fiji, the struggle has been hard. We believe, however, that more can be achieved through collaborative efforts. Fiji's disability community await the launching of AusAID's Disability Strategy, which will indeed be of much assistance to countries in the Pacific and Asia.

I have the same rights as you*: Consequences of using the rights-based approach in Fiji¹

Deborah Rhodes, Australia Pacific Islands Disability Support

Introduction

This paper focuses on outcomes of research into the experiences of four Fijian disabled people's organisations (DPOs) which used the rights-based approach between 1999 and 2004. The four organisations — Fiji Disabled People's Association (FDPA), Fiji Association for the Deaf (FAD), United Blind Persons (UBP) and Spinal Injuries Association (SIA) — incorporated the approach in their planning, advocacy, networking and service delivery activities. They did so within a supportive legislative and institutional environment and within a relatively receptive social context.

International context

In the last five years, a significant proportion of development agencies and civil society organisations (CSOs) internationally have adopted the human rights approach or the rights-based approach to their work. The approach involves using Articles from human rights conventions or other sources as, inter alia, a basis for, or at least to inform, the setting of organisational or development objectives. The approach is also used to determine and prioritise activities, particularly advocacy agendas.

The consequences of using such an approach have not been widely researched and there appears to have been little research on the relative impact of the approach in different settings or among different groups or types of agencies. A study of the consequences of using this approach, even in one local setting, will hopefully increase understanding about why so many organisations have adopted it and inform those who may wish to determine whether the approach may be valuable to them.

The Fijian context

A number of factors relating to Fiji's history of engagement with human rights issues have influenced the nature and extent of contemporary consequences of the use of the rights-based approach. These include:

- government ratification of all key human rights conventions since 1948 (Universal Declaration on Human Rights);
- around 20 years of public discussion on human rights issues in Fiji, particularly in relation to women's and Indigenous rights;
- inclusion of human rights language and concepts in the Fiji Constitution;
- active civil society organisations and discourse;
- existence of the Fiji Human Rights Commission and its increasing public profile;
- commitment of the Fiji National Council for Disabled Persons to issues related to people with disability;
- recent history of increased levels of organisation by people with disability themselves evolving either from organisations which provided welfare services for people with disability or in reaction to them;
- gradual and small-scale shift in approach over time from a medical approach to a rights-based approach; and
- strong leadership by people with disability in the past decade.

Summary of research

The research was undertaken in Suva, Labasa, Sigatoka and Rewa and the consequences of using the right-based approach fell into three categories: for individuals; DPOs and; society and national government.

Consequences for individuals

Increase in confidence and self-esteem

I feel better. I feel good. I feel equal. I feel every right to walk about with or talk with [non-disabled people]. I have the right to go places ... Before I was always shy ... and now I feel stronger in myself (pers.comm. Felise, 24 April 2004).

The adoption of the rights-based approach has resulted in increased levels of personal confidence and self-esteem among office bearers and members of DPOs in Fiji. These impacts were the result of a combination of the attainment of new knowledge by individuals and perceptions that this new knowledge can result in positive change. Changes identified include attitudes by other people towards disability issues generally and people with disability specifically, and improvements in the social, economic and physical environment for people with disability.

New knowledge gained through the rights-based approach encompassed three key understandings that people with disability are: legally regarded as equal with people without disability; protected from discrimination by international and

national legislative frameworks; and have the same right to access education and health services, employment, public facilities, information and all other socio-economic services as anyone.

For most participants in this study, this knowledge was only recently acquired. A few long-standing office bearers in the Suva-centred disability sector have understood the concept for many years. Many people with disability, particularly those outside Suva, did not yet have any understanding of the concept. Those who did have the knowledge linked it to significant improvements in their self-perception. The knowledge they gained changed their views of themselves as members of families, communities, groups and society overall. Their initial experiences of applying such knowledge further confirmed the value of the concepts to their lives and their work as volunteers and staff of DPOs.

Other examples of increased self-esteem and confidence given by participants in the research include:

I feel that when we compare back to five years, I have noted many changes that have taken place. And it feels good. It feels like society now is accepting us. It feels good even in terms of others that are coming after us, those in school, those that are young (pers.comm. Shiva, 21 April 2004).

Due to us attending workshops and sharing information ... we are more educated, we have confidence in ourselves to talk for ourselves (pers.comm. Ayeesha, 17 April 2004).

So the rights-based approach has given confidence to people to be able to go out anywhere, any place, [with] anybody (pers. comm. Solomone, 22 April 2004).

... compared with five years or ten years back, right now I feel very confident, especially when I am in public. I think I should thank all the work ... that has been done to make the public aware of disabilities. It was quite hard for me to socialise, even with people with disabilities, but ... now I feel very confident. I feel very proud of who I am and my disability ... I have accepted it. I have come to terms with it too. It has really built my confidence in who I am today and what I have achieved (pers.comm. Finau, 17 April 2004).

Increased participation

Office bearers of DPOs reported increased levels of participation by individuals in activities and increased requests made to disability groups. An office bearer of the Spinal Injuries Association for example, reported:

People have been coming in ... They are voicing their concerns now.... 'we should have this or we should have that.' Before it

was not like that. Only a few people [had] this knowledge and understanding. They would talk among themselves but were not comfortable to speak up. But now it is changing (pers. comm. Shiva, 21 April 2004).

Changed perceptions

In the past, people with disability considered that the broader community saw them in negative terms. As awareness of disability issues and disability rights has increased, individuals with disability have described feelings of reduced embarrassment and shame, increased freedom and a new confidence. Most participants in this research commented on this change. For example, one office bearer said:

I think now ... we have more confidence in handling a matter. For example, if I walk down the street [now], people will think [differently] from what they used to think about me. And they look at us in a different way. Before, I used to be afraid to go into town. I used to feel ashamed knowing about what the people [thought] about me. But it's not like that now (pers. comm. Shiva, 21 April 2004).

Increased cooperation and self-representation

Cooperation between individuals with similar disabilities and individuals with different types of disability is a key element in individual confidence generated by the adoption of right-based approaches. One senior office bearer said:

We have seen in the past that [other] people were talking on our behalf. It has been fairly recent where people with disabilities have realised that we have to speak on our [own] behalf ... and [we have seen] ... the impact is greater (pers. comm. Ayeesha, 17 April 2004).

The combination of cooperation among people with disability and self-representation is inspiring for others, effective in terms of impact and also occasionally very challenging in practical terms.

There was some suggestion that some people felt threatened by individuals with disability now representing themselves:

People who first raised the issue of disability in Fiji in the 1970s ... felt they would feed us three meals a day and put us in sheltered workshops and that is how our lives would end. And ... those people are feeling threatened [now] (pers.comm. Ayeesha, 20 April 2004).

One long-standing member of FDPA indicated that in his experience, while such a reaction occurred initially, it was soon overcome:

These approaches, first of all, when [they are] starting ... threaten the community. [People in the community think] 'they are challenging us'. So government and the people are sort of threatened, and they stand back. But after being consistent and being persuasive in trying to get things across about the rights of these people into higher levels of government, then people think, 'Oh yes, this is okay' (pers.comm. Solomone, 22 April 2004).

The situation outside Suva

The situation for people with disability in Fiji outside Suva remains largely one of discrimination and isolation (Macanawai and Rokosuka 2003:1). For example:

here they ... tell you to sit in the corner, keep quiet and wait. That's the sort of attitude we get around here (pers.comm. Mara, 23 April 2004).

We are just neglected now. People make fun of us and all sorts of things, like when we go into town, people talk about us. We don't have equal rights, we have to keep quiet (pers.comm. Chandi, 23 April 2004).

The consequences of the rights-based approach for individuals were largely limited to Suva until late 2004, except for:

- the launch of the FDPA Branch in Labasa;
- the initial stages of reactivation of the Nadroqa/Navosa Branch in 2004; and
- participation by people in western Fiji in an FDPA training programme in early 2003.

Implications of increased self-esteem

At the individual level, the study found contributory relationships between the rights-based approach and increased individual self-esteem. This had impacts on self-esteem and motivation; higher quality advocacy and service delivery; and sustainable development outcomes for people with disability.

Future implications for individuals will include increased motivation to achieve more change. Several interviewees mentioned their plans to initiate new activities, such as a job club for people with hearing impairment or small income-generating activities for unemployed members, greater promotion of the concept of the rights of people with disability, and greater cooperative activity among and between people with disability and others.

Consequences for organisations

DPOs in this study share elements of a common rights paradigm — that people with disability have rights, and that these rights need to be promoted and protected. These organisations also

share the belief that self-representation is critical for people with disability, demonstrated in their adoption of the international disability movement slogan 'nothing about us without us'. They have learned from other social movements that 'change has to start with action by the oppressed' (Harris and Enfield 2003:18).

Increased cooperative work

FDPA's mission statement states that its role is to 'facilitate, realise, support and promote the equalisation of opportunities for the full participation of people with disabilities ...' (FDPA nd). The organisation:

- emphasises that it is a cross-disability organisation;
- promotes increased interaction between people with different disabilities;
- shares a commitment to promoting and protecting the rights of people with disability with its affiliates, based on the experiences and views of people with disability themselves; and
- practises and promotes self-representation (while the idea of working as a coordinating body for groups of people with different disabilities is not unique to the rights-based approach, the concepts have arrived in Fiji simultaneously).

In contrast with the medical and social models, the rights-based approach specifically promotes the right of people to organise and advocate for changes in groups with common interests. Within disability discourse, the rights-based approach implies that the link between individuals in organisational terms is their right to work together to protect and promote rights, rather than their various disabilities.

In the past few years ... I have noticed the strong support of the members of FDPA, where they have come together and worked collectively with affiliates and branches to voice our issues (pers.comm. Nanesi, 20 April 2004).

Increased capacity in DPOs

The deliberate efforts by people with disability in Fiji to shift from a position where they are being spoken about to a position where they speak for themselves, reflects a commitment to building capacity among people with disability at the organisational level. Shiva identified this emphasis when he noted:

For NGOs like FDPA, we mostly look at developing our own human resources, in terms of helping our members to speak for ourselves, rather than ask others to speak on our behalf. So we are trying to build our human resources, whereas other NGOs look for funds to develop their projects (pers.comm. Shiva, 21 April 2004).

I know now when we open our branch here ... people are going to listen to us. We will be in a group. Before we were alone, so it was very hard to speak out. Before we really felt that no one will listen to us, and now it's good that we have a group, that we can talk to others and we can support each other and with a group we can voice out our rights (pers.comm. Chandi, 23 April 2004).

Enhanced cooperation between organisations

Discernible changes in the practises of other organisations towards disability issues have occurred since the rights-based approach was adopted. The Fiji Human Rights Commission's forum to address the rights of people with disability was mentioned by several participants in this study as the first time they saw evidence that disability groups were treated respectfully by representatives from other CSOs.

Greater recognition by and levels of engagement with other CSOs have bolstered confidence and self-esteem among members of FDPA and its affiliates, contributed to greater awareness across civil society of disability issues, and enhanced inclusiveness.

Practical organisational changes

The use of the rights-based approach in FDPA's advocacy activities has already contributed to success in relation to promoting the rights of people with disability in practical ways including increased access to information, education, employment and public spaces.

Examples include: the use of voice-overs on weather forecasts and lottery results, so people with visual impairment can access such information; increase in the number of kerb ramps on the streets of Suva; establishment of an employment team and a job club resulting in ten members obtaining employment in 2004; support for four members with hearing impairment to enrol in a mainstream high school in 2005 after successfully completing Grade 8 exams (these students would otherwise have not attended any school); and the approach of feature writers in two national daily newspapers, who now focus on abilities and strengths of people with disability.

Centralisation of organisational change and impact

As with many new paradigms and development practices relevant to organisational change, initial changes more often occur in capital cities. At the end of 2004, the rights-based approach had not yet had an impact beyond Suva, though plans were in place to strengthen FDPA's reach and profile to branch levels during 2005.

People with psychiatric disability

DPOs included in this study include and represent members with a variety of physical disabilities but at the time there was no participation of groups representing members with psychiatric disabilities.

In 2004, a new group, the Psychiatric Survivors Association of Fiji, was formed. Its formation was encouraged by the efforts of FDPA officials and a senior staff member at an institution for people with psychiatric disability in Suva (pers. comm. FDPA advocacy officer, June 2005).

FDPA considered that people with psychiatric disability were missing opportunities to advocate for their issues, to recognise their rights and to represent themselves in policy and programmes related to their rights. The use of the rights-based approach by FDPA contributed to the development of this group. In late 2004 this group began to participate in FDPA meetings and activities.

Consequences for government and society

Suva is quite like a developed country. Labasa is developing and the attitudes of the people will take time to change (pers.comm. Mara, 23 April 2004).

Ten years ago, we never thought of getting an appointment with the Prime Minister or any Minister. But now we can get an appointment any time (pers.comm. Solomone, 22 April 2004).

Culture

Disability was sort of a taboo, something that should be hidden, something that has to be closed [away] (pers.comm. Solomone, 22 April 2003)

This research found mixed views on whether the rights-based approach was a good match with perceptions of Fiji culture, partly reflecting the mixed views and complex nature of culture in Fiji. Some considered there was a clash between the approach and traditional views of disability, because traditionally people with disability were hidden. Others considered there was a good match because traditionally people with disability were treated equally and with respect.

Public awareness

Notwithstanding negative attitudes towards disability and people with disability in some cultural contexts, there have been changes in attitude in some parts of Fijian society as a result of the use of the rights-based approach. These changes are partly caused by increased levels of activity and the raised public and media profiles of self-help DPOs. The media's representation of disability issues and attitudes of other CSOs towards disability issues has also altered.

Now things have changed and [through increased media coverage] people understand a bit more about disability ... and they are more willing to help and give us opportunity (pers. comm. Vera, 17 April 2004).

Using this approach, I have seen that there is more awareness. The public comes to know and understand more about people with disability and their needs ... Whenever I am in a taxi for example, now they usually ask questions and before they didn't. They are more friendly now (pers.comm. Shiva, 17 April 2004).

Increased Government awareness

The rights-based approach provides common ground for interactions between FDPA, its affiliates and Government agencies because the approach focuses on rights accorded to people with disability as defined in the Fijian Constitution and supportive Government legislation. Tension between Government and civil society perspectives on disability issues remains — for example in relation to the extent of policy and programme changes possible, budgetary allocations and acceptable timeframes — but an enabling environment does exist.

Since the use of the rights-based approach, discussions between FDPA and Government officials are based at least partly on a shared understanding of equal rights to education, employment, access public spaces and information.

Conclusion

Use of the rights-based approach by four DPOs in Fiji has positively influenced individuals' self-perception, particularly in terms of confidence and cooperation with others. This directly contrasts with experiences of dependence, marginalisation and exclusion previously experienced by people with disability in Fiji.

The rights-based approach has also contributed to changes in attitudes among and towards people with disability in Fiji, supported organisational change within DPOs, and between DPOs and other civil society and Government agencies. This

has been supported by legislative and Government institutional attention to the rights of people with disability, occurring in the last decade in Fiji and elsewhere.

Importantly, it has reflected a shift from the use of medical, welfare and social models of disability that has been negotiated and selectively imported by Fijian leaders. It has been interpreted to suit Fijian laws and traditions and adapted to suit local social contexts.

Perhaps the control of local leaders and organisations in the adoption, adaptation and interpretation of the approach has led to its positive consequences to date. Had international development or advocacy agencies 'imposed' the approach on their partners, the response may not have been the same.

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Notes

- * Quote from Mara (Interview 23 April 2004) reflecting her newly gained knowledge that people with disability have the same rights as all people.
1. This is a summary of thesis based on research supported by the FDPA.

Traditional perceptions of disability in the Western Highlands of Papua New Guinea

Paul Petrus, Catholic Archdiocese of Mount Hagen

Introduction

In a modern hospital, a doctor diagnoses according to a patient's signs and symptoms. The doctor perceives a possible cause according to his medical expertise and experience and prescribes certain medication for the patient.

A similar process is applied in the traditional highlands of Papua New Guinea (PNG). However, prescriptions are given according to perceived causes. And the perceived causes are presumed according to the signs and symptoms in relation to the relationship of the patient with the bio-physical and the religio-cosmic environment. Wherever necessary, perceived causes of a sickness or disability can be traced back four to five generations.

This paper is based on the author's interest in social issues related to disability. It focuses on traditionally perceived causes of certain disabilities — seeing, hearing and movement difficulties — in the Western Highlands Province of PNG. Some examples are from direct personal experience and some are based on interviews with people with disability and concerned individuals. The case studies are real though pseudonyms are used.

Finally, recommendations are provided because improving the living standards of people with disability is part of the development process. These traditional behaviours and attitudes have a great impact on the modern living standards of the concerned individual, family and the society at large.

In this region of PNG, people with disability generally attract sympathy and pity. Wherever possible, others try to help them live a normal village life. People with severe disability cannot participate actively in social activities. They cannot contribute actively in bride prices, compensations, take part in tribal fights or any other social activities. And the community, with respect and compassion, do not have high expectations of them. But those who do not have a severe disability are expected to fulfill their roles and responsibilities in society.

Commonly perceived causes

Some of the commonly perceived causes of various disabilities in the Western Highlands Province were also observed by Gibbs and Petrus (2006:11) in the Lufa area of the Eastern Highlands Province, and are similar in most areas of the PNG highlands.

Disobeying taboos

Disobeying taboos is a common cultural belief in many regions of PNG. Taboos include entering a forbidden area, such as the dwelling of a bush spirit, or, for a male, committing adultery among female family members including extended families. Disobeying a taboo is believed to lead to chronic illness, disability and social problems.

According to older people, common disabilities include swollen knees resulting in movement difficulties, or a mother giving birth to a baby with disability. A traditional belief is that a likely penalty for entering a forbidden area is deafness and intellectual disability.

Sorcery

PNG highlanders believe sorcery causes illness, death or impairment. Disabilities that can be caused by sorcery include blindness, chronic body aches, paralysis and swollen legs and arms as the following example shows:

Mathew is from the Western Highlands. He is married with two wives and two children. According to Western medicine, Mathew has arthritis and the swollen joint in his legs and hands prevent him from working in his gardens.

Mathew was prescribed medication but has never taken it. He believes his ailment is caused from the time, many years ago, when he punched a coastal man. He believes this man cast some sort of spell on him. Mathew has spent a considerable amount of money on traditional doctors to remove the sorcery, with no improvement so far.

Spirits

A traditional religio-cosmic worldview remains very strong among the people of the Western Highlands and elsewhere in PNG. Most Western Highlanders believe spirits of the dead and the bush can cause illness and permanent disability.

Jacinta is a young woman who has married and divorced several times. She has a hearing difficulty. Her parents say it is because when she was nine, Jacinta trespassed into a forbidden area. Local people believe this particular area is inhabited by the bush spirit *Tepra*.

It is disrespectful to disturb a bush spirit's dwelling without good reason. People avoid this place. However, as a small girl, Jacinta did not know and went in the forbidden area to collect mushrooms. In retaliation for intruding, she was slapped on the ears by *Tepra*. Therefore, today, she has a hearing impairment.

People believe spirits of the dead live around villages. The most dangerous spirits are those of people who were killed secretly by their own tribesmen and families. And, people who die a disrespectful and painful death are always revengeful. For instance, a sick father not properly treated by his children before his death will definitely take revenge as a spirit. (See, for example, Strauss 1962:108-136 for details of the complex relationship between the dead and living in the Western Highlands).

Here is a classic example:

Tem is from the Moge people of the Western Highlands. Between 2003 and 2006, his father, two paternal uncles and a cousin's brother died. According to medical reports, Tem's father and one uncle died of tuberculosis, the other uncle died from mouth cancer and the cousin's brother died from HIV/AIDS.

Tem's father had movement difficulty due to swollen arms and legs for the three years prior to his death. He stayed at home, depending on his children and wife, and finally died in 2003. The uncle with mouth cancer had speech difficulty for two years and suffered great pain before his death in 2006.

Most people in the village were suspicious of the deaths. The men in the village said they believed Tem's father and the others knew of a past murder of some tribesmen. When each of the sick men were on their death beds, the village men asked them to confess any secrets, but each respectively declined this invitation.

After all four men died, Tem's family organised a big feast for the village. They openly declared that if there was any curse or any spirits who sought revenge then they were sorry, and asked for forgiveness.

No misfortune has apparently befallen the family since the big feast. This incident served to strengthen people's belief in the spirits of the dead as a cause of misfortune.

Accidents

Accidents are not always taken for granted, especially when more than one accident happens in a particular family. Traditional

root causes will always be assumed for traffic accidents, injuries in tribal fights, accidental fire and other misadventure causing death or permanent impairment.

Traditionally, accidents happen because of a past bad deed or misfortune among the victim or family members. Therefore, after an accident occurs, relatives gather to discuss possible curses laid upon them by spirits of the dead or other possible causes.

Thomas has four brothers and three sisters, all of whom are married. In the last ten years, there have been four accidents in the family: Thomas's third eldest sister injured her right leg, resulting in permanent movement difficulty requiring the aid of crutches; Thomas' fifth born son died in a car accident; and, in separate incidents, Thomas' brother's wife and his brother-in-law sustained minor injuries in car accidents.

Though medical attention was considered, these incidents were unusual. The family gathered to ask if there were any curses against the family by spirits of the dead, tracing back three to four generations, or whether anyone had secretly committed adultery, theft, or murder within the community.

Western Highlanders believe these issues can cause family misfortune and disturb harmonious social relationships. Social relationships are critical to normal life in any Western Highlands' traditional society. Thomas' family believed it needed to mend social relationships to better their life.

However, nothing concrete was discovered and the family is living in an uneasy state expecting additional misfortune.

God's punishment

Faithful Christians perceive some of their disabilities as a punishment from God, calling them to repent and be his disciple.

A mother who suffered Parkinson's disease for five years felt God had punished her. She had been a faithful Christian and participated very actively in church activities until a few years ago, when she left the church. When she became sick, she was convinced it was a punishment from God. She killed a pig as an offering and repented to God. But she still has Parkinson's disease, and has become more devoted to God. She is convinced that one day, God will have mercy on her and heal her sickness.

Conclusion and recommendations

Disabilities have their own traditionally perceived causes and a medical report does not satisfy the victim or the

family and villagers. In most cases, Western Highlanders believe misfortunes happen because of disturbances in social relationships, and revenge is a path to restoring normal social relationships.

Instead of seeking medical attention for their disabilities, including tuberculosis, HIV/AIDS and cancer, people spend a lot of money and other resources on feasts and traditional healers to cure their disability. Due to this, some curable impairments are left untreated. If people are to believe in medical reports and seek modern disability services, these behaviours and attitudes have to be discouraged.

Concerned organisations need to raise awareness on the causes of disability, and the services available to people with disability. As Thornton and Pirpir (2008:64) suggest, health workers and community based rehabilitation volunteers should take the lead on promoting disability awareness.

Awareness of a National Disability Day is not enough. Consistent awareness is required. Trinit FM, a local Catholic radio station in the Western Highlands, has a weekly disability awareness program. But for lasting impact, more research on disability and other related issues in PNG is required.

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Women with Disabilities Pasifika Network

Sainimili Tawake, Women with Disabilities Pasifika Network

Introduction

The Women with Disabilities Pasifika Network (WWDPN) was established in December 2003, following the first Pacific regional forum for women with disability in the Pacific. It advocates for issues concerning women with disability and represents women from Australia, Cook Islands, Australia, Fiji, Kiribati, New Zealand, Samoa, Solomon Islands, Tuvalu and Vanuatu.

WWDPN's mission is to work towards a Pacific that recognises, respects and promotes the rights of women and girls with disability.

Its objectives are to:

- build the capacity of women and girls with disability through the provision of capacity-building training and education;
- raise the profile of women and girls with disability and the WWDPN within national, regional and international organisations; and
- promote issues, lobby for and advocate on behalf of women with disability at national, regional and international levels.

The situation of women with disability in the Pacific

Apart from general disability and women's issues, such as lack of education and employment opportunities, the needs of women with disability are very diverse and include sexual reproductive health and rights, forced abortion, and vulnerability to sexual violence and abuse. Issues such as these lead to further discrimination against women with disability. Other often unrecognised difficulties are the power struggles between women with and without disability, and those between women and men with disability. These need to be addressed.

WWDPN Activities

WWDPN has organised two regional and one national capacity-building seminars where participants revealed personal stories of the realities they face in their everyday lives. The network has also actively collaborated with other regional women's organisations promoting women with disability issues. WWDPN played an active role in mainstreaming women with disability issues within national, regional and international organisations. In late 2007,

a meeting was conducted to review WWDPN and its status; this was attended by women with disability and carers who saw the need to develop the capacity of the network.

In early 2008, two WWDPN members attended a regional seminar on the Elimination of Violence Against Women, organised by UNIFEM's Pacific Office and the Fiji Women's Crisis Centre and the Asia Pacific Disability Forum in Bangladesh. Here we presented findings of a desk review on the status of women and girls with disability in the Pacific, commissioned by the United Nations Development Program Pacific Office and the Secretariat of the Pacific Community (SPC).

The commissioning of this desk review was a result of work the network had done in raising the recognition of women with disability issues within organisations such as the United Nations Development Program, SPC, UNIFEM, the Pacific Forum Secretariat and regional NGOs. As a result of the network's efforts, a number of NGOs now consider women with disability within the planning and implementation of their programmes.

Challenges

- Financial resources: particularly involving funding for the formal establishment of WWDPN such as planning its constitution, registering the network and running its secretariat.
- Human resources: putting our thoughts into words and packaging our work.
- Tackling minority issues.
- Support: some other regional disability organisations do not seem to consider that it is the right time to establish a network such as WWDPN.
- Some mainstream women's organisations and other NGOs are blind to the need to take on board women with disability issues.

The future

WWDPN has the capacity to grow into a powerful and active organisation of women with disability in the Pacific if given the opportunity and financial and technical support. It believes in working in partnership with and alongside other organisations that promote disability and women with disability issues. It does not see its establishment as duplicating the role of other

regional organisations but believes that women with disability need their own space to learn at their own pace, to develop and confide among themselves on their own issues.

WWDPN, as a movement of women with disability, is well placed to advocate for and lobby issues concerning women with disability. Although there are some women's groups that have included women with disability in their programmes, much more work needs to be done to influence the women's movement

and national women's machineries to support the inclusion of issues of women with disability in national plan of actions.

WWDPN will continue to identify and address issues facing women with disability in the Pacific. This includes working with national, regional and international organisations, working towards the development of a national disabled women's network, and developing community understanding of the issues facing women with disability.

Innovative approaches to successful advocacy: Vision 2020 Australia

Jennifer Gersbeck, *Vision 2020 Australia*

Introduction

As the peak body for more than 50 Australian eye health and vision care organisations, Vision 2020 Australia leads advocacy efforts and raises community awareness to prevent avoidable blindness. Together with its members, Vision 2020 Australia has successfully raised the profile of eye health and vision care and secured the endorsement of a national plan for the prevention of blindness by state health ministers across Australia.

Established in October 2000, Vision 2020 Australia is part of 'VISION 2020: The Right to Sight', a global initiative of WHO and the International Agency for the Prevention of Blindness.

The organisation has concentrated primarily on preventing avoidable blindness and improving vision care within Australia. However, considerable effort has also been directed at achieving a commitment from the Australian Government to tackle prevention of blindness in the Asia-Pacific region.

Recently, Vision 2020 Australia has adopted a number of successful innovative approaches to advocacy. They were the result of careful planning and a focus on four key areas: encouraging collaboration within the Australian eye health and vision care sector; establishing credibility as a national peak body; utilising a strong evidence base; and developing a sound strategic approach.

Facilitating collaboration

One of the key indicators of Vision 2020 Australia's success is the facilitation of member collaboration. Over the last few years collaboration among its members has visibly strengthened.

Collaboration is encouraged through a variety of mechanisms, including convening networks, committees and working groups that provide a specific forum for specialised policy areas and bring together members working across a range of settings to share knowledge and expertise.

There are a number of opportunities that provide a platform for collaboration such as strategic planning days, annual member forums, parliamentary friends' group events and World Sight Day activities. Facilitation of member collaboration increases sector-wide understanding of relevant policy issues, promotes networking between members, and increases strategic and opportunistic advocacy and marketing and PR initiatives.

Effective communication with stakeholders is essential. While committees and working groups enable good communication

flow between members and within Vision 2020 Australia, annual member forums provide an opportunity for members to collectively set priorities for the year ahead and take part in discussions to direct Vision 2020 Australia's advocacy agenda. Strategic planning and organisational issues are also considered during these events.

To further enhance its communication, Vision 2020 Australia has established a member portal on its website enabling members to keep up to date with current news and events and government initiatives across the country. It also includes an online discussion forum where members provide comments and share thoughts on current issues facing the Australian eye health and vision care sector.

The combination of Vision 2020 Australia's communication efforts ensure that members have a clear understanding of goals, know exactly where they are headed and how they are going to get there.

Examples of successful member collaboration include:

- The development and government endorsement of the *National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss* (see Commonwealth of Australia 2005). This is a framework initiated in response to the World Health Assembly Resolution 56.26 on the elimination of avoidable blindness, and sets a blueprint for nationally coordinated action on eye health and vision care by governments, health professionals, community organisations, industry and individuals.
- There has been success with collaborative submissions under the National Eye Health Demonstration grants funded by the Australian Government. Over the last 12 months, 24 projects have received funding totalling \$2.5 million, with the majority going to Vision 2020 Australia member organisations who are working together to deliver a range of eye health and vision care projects across Australia.
- And finally, an excellent example of what can be achieved through collaboration is the commitment by the Australian Government to support Vision 2020 Australia's 'Regional Plan to Eliminate Blindness and Vision Impairment in our Region

(Regional Plan)' (see Vision 2020 Australia 2007) through the development and implementation of AusAID's Avoidable Blindness Initiative.

Establishing credibility

It should be no surprise that governments want to deal with one representative body. However, before they will listen, that body needs to be able to demonstrate that it truly represents the sector. Governments want to see that the sector does collaborate, and they also want to hear consistent messages. Effective communication mechanisms ensure that the sector does speak with a unified voice, and Vision 2020 Australia actively seeks agreement on all key issues with members before speaking with government.

To establish credibility it is important that you understand your subject matter, and that you can speak with a level of authority. Vision 2020 Australia achieves this by involving experts from within its membership on delegations to government. Organisations must also be highly regarded within the right circles. This involves building and maintaining a good reputation with key stakeholders.

Vision 2020 Australia has learned that one of the deciding factors between successful and unsuccessful advocacy is how well it understands its target audience, including its own member organisations, state and federal governments and other external stakeholders. In order to influence key decision makers, it is essential to understand their priorities and policy drivers, and Vision 2020 Australia has built and maintained strong and mutually rewarding relationships with ministers and government officials.

A recent approach adopted by Vision 2020 Australia to better understand its target audience and to influence key decision makers, was the establishment of the Parliamentary Friends Group for Eye Health and Vision Care. This group was formed in 2007 and has developed a strong membership base of Federal Parliamentarians from a variety of political parties and portfolios.

Members meet bi-annually over dinner at Australia's Parliament House and listen to keynote speakers address current issues in eye health and vision care. These events have built awareness around the impact blindness and low vision has within member electorates and has helped Vision 2020 Australia and members to identify and action future initiatives.

Utilising evidence

With guidance from its members, Vision 2020 Australia relies on the use of a strong quantitative evidence base to support all advocacy efforts.

A 2004 report produced by Access Economics in collaboration with the Centre for Eye Research Australia, on

the economic impact and cost of vision loss in Australia (see Taylor et al 2004), is one example of the valuable resources Vision 2020 Australia has at hand.

Three subsequent reports look at investing in sight: strategic interventions to prevent vision loss in Australia (see Taylor et al 2005); the impact of age-related macular degeneration (see Taylor et al 2006); and the economic impact of primary angle glaucoma (see Taylor et al 2008).

Vision 2020 Australia has found that illustrating the cost of avoidable blindness and the economic impact of untreated eye conditions builds a compelling case for key decision makers to take action. Vision 2020 Australia has also found it helpful to utilise population health surveys conducted by various state governments across Australia. Together with hospital data, Vision 2020 Australia has been able to build a solid evidence base to present a strong case to government.

Global reports and publications do play a role, but national governments require local evidence. Continually building the evidence base is important. Vision 2020 Australia sources information from its member organisations and has recently embarked on a project to work with government in setting key research action areas. This project brings together Vision 2020 Australia's members involved in research to identify the breadth of research activity already being undertaken and identify knowledge gaps.

Developing strategy

As outlined earlier, understanding your target audience is critical to the success of any advocacy strategy. Equally important is being clear about the direction you are heading and the goals that will enable you to get there.

Without doubt planning is essential. Without a comprehensive plan it is easy to be distracted by unimportant events that are not key to achieving your objectives, and monitoring your progress against the various action areas is vital to ensure you are on track and to enable you to demonstrate milestones achieved.

'A Plan to Eliminate Blindness and Vision Impairment in our Region' (see Vision Australia 2020 2007) is the most recent example of where a solid evidence base, coupled with strong collaboration and a clear strategy, presented by an organisation with government credibility, has resulted in a major milestone for the global eye health and vision care sector.

With 2007 an election year, Vision 2020 Australia campaigned for the inclusion of global eye health and vision care on the election agendas of the Government and Opposition.

Together with members of Vision 2020 Australia's Global Committee, the regional plan was produced, demonstrating the need for eye health and vision care intervention in the Asia-Pacific region. The plan was based on a costing model that

outlined what was required to deliver an effective and sustainable eye health and vision care programme over a ten year period, and was divided into three phases requesting a total Australian Government commitment of \$600 million.

Estimated costs were extrapolated from in-country member programme data, which gave an accurate assessment of the cost of eye health and vision care intervention in 19 of the Australian Government's priority countries currently receiving Australian international aid. Once these costs were established, Vision 2020 Australia was able to confidently demonstrate to Government what could be achieved with the proposed funding and within the specified timeframe.

In October 2007, both major political parties made significant pre-election funding commitments to implement the regional plan, and the new Parliamentary Secretary for International Development Assistance pledged to provide \$45 million to fully fund the first phase of the plan over two years.

On 13 May 2008, the new Australian Government announced its international aid budget allocating funds for the first time to eliminate avoidable blindness in the region, fulfilling their pre-election commitment. These funds were committed to address primary and secondary eye care needs in the region and expand the number of eye health workers through support to training centres, medical colleges and teaching hospitals.

Running parallel to the development of the avoidable blindness initiative, the Government also committed to develop a broader disability strategy. The prevention and treatment of blindness and low vision will feature in this strategy as the Government moves to integrate disability into its future aid commitments.

Summary

As a national peak body, Vision 2020 Australia prides itself on its ability to facilitate collaboration and give a unified voice to

the Australian eye health and vision care sector. Innovation is the key to its success.

While organisations generally demonstrate strength in many of the areas outlined in this paper, an innovative organisation recognises the importance of bringing these four elements together.

If you can facilitate collaboration, establish credibility, utilise the available evidence, and develop and implement an effective strategy, you will succeed.

Vision 2020 Australia is very proud of its achievements and the support shown by its member organisations. Their continued commitment will ensure Australia and the Western Pacific Region make a significant contribution to the global goal to eliminate avoidable blindness by the year 2020.

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The role of volunteers in assisting disabled people's organisations

David Hill, Australian Business Volunteers

Bringing disabled people out of the corners and back alleys of society, and empowering them to thrive in the bustling center of national life will do much to improve the lives of many from among the poorest of the poor around the world (Wolfensohn 2002).

Perhaps this should be amended to:

People with disability want more than just being actively involved in national life, rather they seek to be active contributors to national development.

Introduction

Australian Business Volunteers (ABV, formerly AESOP), is a Canberra based non-government, not-for-profit development agency which has, for the past 27 years, played a vital role in strengthening ties among nations by volunteer placements throughout the Pacific and Asian regions.

Its mission is to contribute to sustainable growth in developing communities through the transfer of knowledge and workplace skills using volunteer expertise.

ABV focuses on placing volunteers with extensive skills and experience especially in management, administration and business development. Volunteers are executive, business and tradespeople with more than five years successful work experience in their specialist area.

ABV prides itself on its responsiveness to client-driven requests for development assistance. Clients approach ABV with requests for assistance and the assignments that ABV supports are firmly based on the concept of self-help. Individual assignments are on average from one month to three months in duration. Longer term multi-year programmes consisting of several linked assignments are also undertaken.

Enterprise development and livelihoods

Although largely funded by the Australian Government through AusAID, ABV believes the private sector is the engine for economic development which can alleviate poverty by contributing to economic growth, job creation and people's incomes and livelihoods. It is for this reason that ABV has a specific focus on supporting the development of the private sector.

As well as assisting private enterprises, ABV also assists non-government and community organisations as well as

government agencies, primarily in the areas of management and administration, so that they are better able to deliver quality outcomes and services to their respective beneficiaries.

ABV's history of disability work

ABV has had a long-term commitment to assisting disabled people's organisations (DPOs) in their work to reduce the impact of disability in the Pacific and Asia. The focus of their assistance to DPOs has been predominately in the areas of organisational development and institutional strengthening to enhance the delivery of disability services.

The rationale for this approach is straightforward. Many DPOs are small with limited human and institutional resources, and receive grossly inadequate funding. They therefore face huge challenges in delivering their services to the people with disability in the communities they serve.

ABV has also undertaken assignments in specific technical disability areas such as audiology, special needs education, prosthetic training, and speech therapy. To improve its ability to respond to requests from DPOs for assistance in technical or specialised disability areas, ABV entered into a Memorandum of Understanding with National Disability Services (NDS), the peak disability body in Australia, in 2004.

NDS will promote specific volunteer requests to member organisations who indicate interest in participating with ABV. In addition, ABV has actively sourced many skilled volunteers, including occupational therapists, physiotherapists, speech therapists and other disability practitioners to share expertise in a range of ABV assignments. Further plans are being developed to partner with other organisations in the region to enable ABV to extend this work.

List of assignments

The list of assignments undertaken by ABV is quite extensive. A recent search of the ABV data base yielded a list of 75 assignments undertaken since 1996 in nine Pacific and Asian countries. The earliest assignments were undertaken in PNG in 1996. Table 1 presents a summary of these assignments.

Case studies

The following case studies illustrate the range of work covered in two programmes of assignments.

Table 1: ABV DPO assignments in the Asia-Pacific region since 1996

Country and in-country clients	Number of assignments	Focus of assignment(s)
Cambodia		
Disability Action Council (DAC) DAC is a semi-autonomous national coordinating body in the disability and rehabilitation sector	Eight (1998-08)	Systems development Small business training Special education training Training of community workers Human resource development Management Fundraising and strategic planning
Cambodian Disabled People's Organisation	Five	Management Human resource management Organisational development
Cambodian National Volley Ball League (Disabled)	Six	Financial management Sports wheelchair design and manufacture Quality control in manufacturing
Veterans International Cambodia (VIC)	One	Business development (wheelchair manufacture)
Fiji		
Foundation for Rural Integrated Enterprises 'N' Development (FRIEND)	Two	Develop marketing strategy Redesign and update website
Kiribati		
Tungaru Central Hospital	One	Prosthetic training
Laos		
Lao Disabled Women Development Center	Six	Organisational development Business development Strategic planning Grant writing Financial management Business planning Marketing training
Lao Disabled People's Association	Two	Develop training plan Accountancy training
Philippines		
Tagbilaran City Central Elementary School	Six	Audiology training Computer programme assessment Culinary arts training Restaurant management training Audiological and community awareness training Education programme design for the hearing impaired
Calamba Association for Persons with Disabilities	Two	Sustainable livelihood program
Cebu Learning Centre for Special Children	One	Special education development
Stages Center (Vocational Education-Livelihood-NGO)	One	Special needs teacher training
Sunshine Center (Vocational Education-Livelihood-NGO)	One	Curriculum development in prevocational training for special needs children
Our Lady of Lourdes	Eight	Child therapy training Speech therapist Business and financial planning Rehabilitation programme Paediatric physiotherapy training

Papua New Guinea		
Callan Services for Disabled Persons	15 assignments (1996–04)	Building supervision Construction management Physiotherapy — Train the Trainer
Thailand		
Sirindorn National Memorial Rehabilitation Center (SNMRC)	One	Hospice care training
Disabled Peoples' International Asia-Pacific	Four	Accessibility requirements for construction and hospitality sectors Organisational development and marketing Fundraising capacity building Project planning and project management
Timor Leste		
Ryder Cheshire Foundation - Klibur Domin	Two	Rehabilitation centre management
Vietnam		
Vietnam Friendship Village	Three	Sports programmes for disabled people Business scope and development Organic agriculture techniques
TOTAL ASSIGNMENTS	75	

Lao Disabled Women Development Center (LDWDC), Vientiane, Lao PDR

ABV's program of assistance with LDWDC illustrates the scope of assignments undertaken through long-term programmes of assistance to small DPOs.

Founded in 2002, LDWDC has 35 staff and receives very limited funding. It is a vocational training centre providing training and employment for predominantly Lao women with disability but also for men, in weaving, sewing, handicraft making, paper making and computer awareness skills. LDWDC sells their products in commercial markets to supplement the cost of training, which is paid in part by donations from many organisations, including the Leprosy Mission, Mennonite Centre Committee and many local businesses.

LDWDC contributes to helping isolated women with disability become active economic members of the community by providing training to enable people with disability to return to their community and be self-sufficient and independent.

Their mission is to work with others to provide opportunities for people with disability, promote the ability of people with disability, encourage people with disability to recognise their abilities, and manage the resources of LDWDC to achieve their goals.

ABV delivered six volunteer assignments to assist with organisation and business development. Assistance was provided in strategic planning, grant writing, financial management, and business planning. A follow-on assignment in marketing is in preparation.

LDWDC has many saleable products, but is unsure how to promote them to potential customers and has difficulty knowing which products to offer to foreign markets and which products are better for the local market.

LDWDC was looking to increase its marketing capacity in order to increase sales and, in turn, the number of students LDWDC is able to accept into a yearly training course. To assist in achieving this objective, a current ABV volunteer is providing training in the marketing of handicrafts and graphic design and website maintenance training.

The volunteer is developing, in collaboration with LDWDC staff, a marketing manual and marketing plan. To make the work as concrete as possible, the approach is to provide practical, hands-on experience.

ABV has provided seed funding from an internal staff donation fund to sponsor two female staff with disability to attend marketing training, cultural exchange and a sales opportunity field visit to Luang Prabang which has a more sophisticated and competitive tourism business than Vientiane. Luang Prabang has larger organisations with experience and understanding of the needs of the foreign tourist market, specifically, what designs and product development to target.

The objectives of the study visit are twofold. Firstly, to develop a stronger understanding of the tourist market in general, the handicrafts that are sold and possible market gaps, merchandising techniques, quality of products, pricing, shopping style of tourists and related behaviours. And secondly, to develop contacts and product orders with new customers.

Calamba Association of Persons with Disabilities (CAPWD), Cebu, the Philippines

ABV undertook an initial assignment in 2005 with CAPWD and helped in the formation of the Community Livelihood Advancement Network Multi-Purpose Cooperative (CLAN MPC). The volunteer trained the president and CAPWD board members in the formulation of CAPWD's operational plan for a proposed EcoCentre.

Solid waste management is a priority programme for both the national and local government. In response, CLAN MPC was initiated by CAPWD and organised primarily to become a contributing partner in community development and most importantly the promotion of empowerment for people with disability through sustainable economic and self-reliant activities in line with cooperative principles.

CLAN PMC will also promote the management of a functional materials recovery facility (MRF)/Ecological Centre (EcoCentre) in other barangays (smallest unit of government in the country) within the Visayas area. These will be managed by people with disability in partnership with local governments through a self-help approach and promotion of capital-saving mobilisation programmes in line with cooperative principles.

Now that the EcoCentre is operational, the volunteer will return to review the overall operations and possible expansion plans of the EcoCentre under the management of CLAN MPC.

The goal of the assignment is to assure the EcoCenter's sustainability and sound management to ensure continued employment opportunities for people with disability and other members of the community.

Lessons learned and future directions

Many significant lessons have been learned from ABV's work with DPOs over a period exceeding a decade. Perhaps the most significant is that volunteers do play vital and transforming roles in the organisational development and expansion of DPOs, thus contributing to sustained and enhanced service delivery to people with disability and broader community and national development. Equally important is the assistance volunteers have brought to livelihood, employment and income-generation programmes.

Thus, ABV's focus on capacity building and organisational development of the DPOs will be continued, along with assistance in business development opportunities. Volunteers will also be mobilised to assist in specific disability-related areas, such as speech therapy or special needs education, for example. Strengthening DPOs will enable more people with disability to become active contributors to national development. There are so many vital national development needs to which all people can make a contribution.

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Experiences as a volunteer occupational therapist in India and Solomon Islands

Genevieve Wiley, Occupational Therapist

Background

When I first started studying Occupational Therapy (OT) at The University of Sydney, I was unaware of the component of community-based rehabilitation (CBR). Unlike many health care methods, CBR OT provides people with knowledge about disabilities, prevention and rehabilitation as well as creative ideas on how to provide the services needed in isolated situations.

CBR OT acknowledges the fact that every case is different and no two situations will be the same. CBR occupational therapists (OTs) are also very aware that access to medical equipment is a luxury that many people do not have. For example, there may be a child with cerebral palsy in a remote village but the village is too far away from a clinic to be of help. In this case, OTs would educate the village and the family on cerebral palsy and some simple therapy methods and ideas to help improve function, include the child in daily activities, improve quality of life and prevent further disability. A large part of an OT's job is helping the family and community to become the healthcare worker through education.

In my fourth year of university, I took the CBR elective which gave me the option to travel to India with Operation International. The elective, as well as the meetings leading up to India, were eye opening. I was amazed at how such simple and clear ideas could be used to convey messages relating to rather complex subjects such as disability. The shorter and simpler the message, the more likely it would be for people to remember.

We learnt about working in different cultures and the differences between collective and individual societies. I was introduced to a range of community-based literature and development studies discussing poverty, disability, education, women's issues and how they relate to each other. We were taught that providing education to women reduces fertility rates and infant mortality, about stigma associated with mental illness due to religious beliefs, cultural attitudes to disability, class systems and more.

I was also introduced to a range of teaching methods that could be used in village situations where few people could read, to convey health messages. These were role plays, songs, simple pictures and leading by example. A clear message that my lecturer often repeated was 'keep it simple, stupid', a phrase I continue to apply to any teaching or training I do today. While the theory in the lead up to India was eye opening, the practice was something else.

Indian experience

Before heading to India the group was paired up and allocated assignments scattered through the south of India. Pairs were placed in a range of different community health situations, with each pair living in the community in which they worked. Our roles involved working in schools for children with disability, educating parents, visiting homes, designing play equipment, providing education about positioning, reducing stigma through knowledge, and discussing strategies to prevent further disability from developing.

My partner and I were placed in an institution for mentally ill homeless women, The Banyan (<http://www.thebanyan.org>) in Chennai. The Banyan was a kind of safe-house for mentally ill women who had been thrown out of home or born on the streets. Many women had lived on the streets enduring frequent abuse and rape.

Women were picked up by police and taken to The Banyan for initial health checks and provided with clothing and food. They would then be asked about their family and if family existed they would be contacted. If not, women would remain at The Banyan where they would be provided with medical attention, therapy and training in various activities such as sewing, crafts, block printing and cooking. The women would also be given the opportunity to sell their creations at a store in The Banyan to raise money for the facility.

Initially, my colleague and I spent time familiarising ourselves with The Banyan, its workers, routines and consumers. Aside from being a rather dismal and depressing place to look at, The Banyan was well run and offered fantastic services. Many staff members were women from poor families who were trained to look after people with a mental illness, provided with education, work, food and housing.

The level of services offered was so comprehensive we began to doubt that we could add anything more. The Banyan was focused on women, had a strong ethical foundation, offered a variety of activities and worked to reduce stigma in the community. However, following a routine visit by our supervisor, it was decided that we would assist at Otteri, a branch of The Banyan that was being established for long-stay women.

Otteri was far less established than The Banyan and following discussions with a local OT at Otteri, it was discovered that we could assist in many ways, but with so little time it was

difficult to know where to begin. The women needed life skills training, a structured routine, field trips into the community for social retraining and education on medication management. Knowing that all of this would be impossible to achieve in the short time we had, we decided to work with the local OT and establish a manual filled with ideas and activities that she could use and carry out in her own way with the assistance of local health workers.

In conjunction with this, we demonstrated various ways of performing the activities in the manual such as taking a group of women into town to buy cooking ingredients. Otteri was a challenging environment to work in. With our lack of language skills it was difficult to work directly with the women so we found training the trainer to be the most efficient and sustainable approach.

In India I found that the best way to work within the culture was to watch and learn, keep it simple, train the trainer and use already established methods as much as possible.

Following my time in India I wanted to become involved in more development work and I became involved with Volunteering for International Development (VIDA).

Solomon Islands experience

With VIDA I went to the Solomon Islands in June 2006 to work as an OT for seven months. I had no idea what to expect, and India had taught me that this was a very good way to begin.

My role involved establishing an associate diploma in OT at the Solomon Islands School of Higher Education (SICHE). I worked with an Australian Youth Ambassador and another VIDA volunteer, both of whom had participated in Operation International at The University of Sydney, to teach 13 health care workers from across the nation.

The course was set up as a two year course, of which I would be teaching the first semester. This involved teaching at the college, doing field visits to homes, working at the National Referral Hospital and travelling to remote parts of the Solomons to do student supervision. My students ranged in ages from 30–60 years and came from all over the Solomon Islands to gain important healthcare knowledge that could be applied to their unique and very remote situations.

The Solomon Islands is made up of eight provinces and hundreds of islands, many of which have no cars and where most transport is by boat or on foot. The National Referral Hospital is on Guadalcanal in Honiara and is the main hospital for the Solomon Islands. The nearby island of Malaita has a large hospital that also includes a large mental health component.

Throughout the provinces, clinics provide some first aid and medical check ups but are often poorly stocked or closed. The Ministry of Health's CBR division offers training to locals to become CBR workers whose job is to travel

throughout their region providing equipment and education to families and communities. This is difficult as it can take days to reach one family.

The thirteen students chosen to take part in the Associate Diploma of OT were all very experienced CBR workers who had been trained by the Ministry of Health's CBR division. Once the students and I realised I didn't speak their language very well and they didn't speak my language very well, we settled upon a mix of medico English and Pidgin English which seemed to do the job.

I quickly learnt that my group of mature-aged students much preferred singing, dancing and acting to writing, reading or listening. So I allowed for as much singing, dancing and acting as I could in each class. I found that by acting out scenarios we covered a lot more content than by lecturing. It was much easier to act out being a paraplegic than a bilateral amputee.

At the end of the semester I travelled to remote parts of the Solomons to conduct fieldwork supervision. This was a great privilege and the most amazing experience of my life. I traveled to Temotu, Makira, Malaita and then to Savo/Central.

In parts of Makira I was the first 'white man' a lot of young children had seen. This travel gave me insight into the situations that my OT students would be working in. Not only do they have little to no resources or access to information, but most places take days to walk to, or hours and hours to get to by motor boat, often through rough seas. So what we were doing with the clients became even more important because no one knew when the OT student would next be able to visit.

I saw illnesses and disabilities that are seldom seen in Australia, including club foot, polio, malaria, ring worm and leprosy to name a few. There were also cases where disabilities had been left to become so bad, that little could be done to help.

In Makira I went to one small hut where a family of 14 lived and where two of the children had muscular dystrophy. One child had lost use of all his muscles except his facial muscles and eyes. His positioning had been so poor that his rib cage was completely distorted. This made it hard to re-position him in a more functional position, but we did so using rice bags filled with sand. We provided education on positioning to the family as well as ways to include the child in daily life.

Rural people are very creative and resourceful and once shown what to do many people were able to make splints or walking aids out of things they found in their environment like coconuts, wood and leaves.

A large part of my role was to make people aware that people with disability are equal members of society who are capable of work and play and who should be given the opportunity to live a full and happy life.

Prevention was also part of the education we provided. In the Solomon Islands, many people require amputations due to diabetes and many children contract malaria which can result in cerebral palsy. Falls from coconut trees often result in paralysis and AIDS is also spreading. Providing education to communities on diet, safe collection of coconuts, malaria prevention and safe sex became second nature to the CBR students. I feel we achieved a lot in a short period of time and I am happy to say that the project is still continuing, with the help of VIDA, and the students will be graduating at the end of 2009.

Conclusion

There is an overwhelming need for allied health services in remote and isolated parts of the world where people with

disability are at the greatest disadvantage. It is in these locations that sharing information or performing small actions, you can pass on knowledge to someone who can continue to use it to help people who do not yet have the resources to help themselves. From my experience, the best way to work within a developing country is to watch and learn, teach by doing, keep it simple, train the trainer and use already established methods as much as possible. Singing and dancing also seems to help a lot.

I believe if more university courses offered opportunities to work in remote areas, many more simple and effective projects would be up and running and providing young Australians with insight into other cultures and communities, including those within our own country.

Physiotherapy approaches to disability work in the community: comparison between India and the UK

Christina Lowry, Physiotherapist

This paper reviews my experience working with people with disability in the community in both a developing and developed country — in India and the United Kingdom. It considers the methodologies used and explores the differences and similarities between how physiotherapists may approach their work in very different cultural environments.

Personal background

In 1997 I joined the University of Sydney's Operation India Program (now known as the Operation International Program) for my clinical elective placement. As a physiotherapy student I was paired with an occupational therapy student, also from the university, and embarked on a four-week placement in the rural areas of Kolkata where we worked with local health workers in their Community-Based Rehabilitation (CBR) programme. Our primary goal was to train the local health workers in basic rehabilitation skills. In 1999 and 2001, as the University's physiotherapy supervisor for the programme I accompanied students to India to support them during their clinical placements.

In 2005 I worked for the Hammersmith and Fulham Primary Care Trust Learning Disability Service in London, providing community based clinical management of the physiotherapy service and provision of direct physiotherapy input for service users. I worked very closely with my occupational therapy colleague and in many ways, the multidisciplinary approach adopted in my London work had many similarities to how I worked with my occupational therapy colleague in India. I quickly realised that despite the very different cultural and physical environments, when working with individuals and professional colleagues, I utilised the same skills I had developed in India.

Medical versus social models of CBR

Through much of my training I learnt a great deal about disease and disability and how to diagnose and treat the various conditions we would face as trained therapists. This medical model approach provided us with important knowledge, but it proved to have limitations in the community settings I worked in and with the conditions I encountered. In India, many of the disabilities we faced could not be 'fixed'. Some were permanent disabilities and others would require a long rehabilitation time, where rehabilitation would need to be provided by the local health worker or a carer.

Regardless of the disability, however, these people needed to function in their environment, often with minimal assistance, and needed to do so immediately. It was this key aspect of how I looked at an individual's disability that changed the way I practiced physiotherapy. It was clear that I had to see beyond the physical disability and see how the individual worked and played in their environment and to incorporate the environment and the community in my analysis and therapy advice.

In essence, I adopted a more social or CBR-based model which has a much more holistic approach. This model, as described by ILO, UNESCO and WHO (2004), not only provides relevant rehabilitative services to individuals, but also involves the entire community to remove barriers that may prevent individuals maximising their potential in society. This concept has been adopted in Articles 25 and 26 of the Convention on the Rights of Persons with Disabilities and Optional Protocol and emphasises a human rights approach ensuring the participation of people with disability in their community (UN nd.).

Crossing professional boundaries

One of the greatest challenges I faced while working in India with my occupational therapy colleague was breaking down the barriers built around our professions. It became quite evident that the most effective way we could work together was to adopt certain aspects of each other's profession. Physiotherapists approach a client initially focussing on the disabled body part (for example, the painful elbow), they diagnose the problem and attempt to repair the body part (for example, reduce pain, increase movement).

Although a physiotherapist will look at the disabled body part within its functional context (for example, requiring a pain free elbow to work on a factory production line), this is often secondary to 'fixing' the problem. Occupational therapists, on the other hand, focus initially on the environment, which then leads them to the individual and their disability. These two opposing approaches initially proved to be a difficulty in our working relationship and it wasn't until we recognised this and started to adopt each other's style of practise that we finally began to develop an effective working relationship.

I used the same approach working with my occupational therapy colleague in London. Her experience working with our clients was an asset and I followed her lead on several joint visits. I used a similar methodology to that which I adopted

in India and considered the environment before analysing the individual's specific problem. This often proved difficult. Unsurprisingly, both in India and London, when our team arrived, people focused on their specific ailment and often expected quick fixes. However, that was often not possible.

Despite adopting many of the occupational therapy approaches and methodologies, it was essential that I knew the limitations of my expertise and skill, and acknowledged that I was not a trained occupational therapist. This was most evident in India when one of our clients presented with a stiff elbow. Following a short physical assessment we realised she had fused radial-ulnar joints, meaning that with her elbow bent at 90 degrees she could not turn her forearm to face her palm up or down.

One of this client's most important tasks was to carry water in a large water pot. Physiotherapy could do nothing for her situation. It was more the adaptive occupational therapy ideas that would assist her to function in her local environment. Together, the client, my occupational therapy and local health worker colleague and I worked out a solution. I realised that often the most simple approach is the most effective and that despite my training, I was often not the 'expert' when it came to the functioning lives of my clients, but rather it was the client themselves and those who care for them.

Sustainability and independence

One of the key values of the Operational International Program (as with many international development programmes and projects) is to ensure sustainability. There are few fully qualified physiotherapists in rural India and, within CBR principles, using minimally trained health workers to undertake certain rehabilitation delivery is a cost effective approach in resource poor settings (WHO 2004).

Rather than providing direct patient care, the aim was to enable local health workers to teach carers of people with disability to undertake basic rehabilitation techniques. This method was very similar to work I conducted in London where I was a sole physiotherapist for a community clientele of approximately 200 people. Not all of these people required the services of a physiotherapist, but some required care on a daily, or weekly basis.

The load was too great to enable me to provide much direct patient care and, as is often undertaken in the community setting, I taught my clients' carers how to perform the required rehabilitation. Despite working in a relatively wealthy country and working for the public National Health Service, I was still required to consider the issue of sustainability and how best to allocate my limited time and resources. That meant giving carers the skills and techniques so that they could provide care to my clients, with regular supervision and review from me.

The services of a physiotherapist is a limited resource within the community setting regardless of whether you are in a developing or developed country and an important approach is the transferral of skills and knowledge to those with less formal rehabilitation training.

Cultural beliefs and client expectations

Working in India, we were faced with many religious and cultural beliefs that were often difficult for us to understand. Being sensitive to others' beliefs is very important when working in a community. Even if we did not believe in some of their ideas about disability — as being, for example, the result of divine intervention — we had to consider that such cultural and religious beliefs are deep seated and would not be changed by our words.

But there were limitations. Some beliefs appeared to support unfair cruelty. This was highlighted in a situation in a very rural village in the centre of India. At one village gathering, we were presented with a young girl of about ten who was labelled 'mad'. She was deaf and unable to speak, but otherwise had no other physical or obvious mental disability. The local health worker presented her to us saying that every now and then, she would go into her family's kitchen and break pots and pans and scream in a wild rage. The local village doctor thought she was possessed and so the family, during her time of rage, would tie her up at the front of the house and beat her.

With further questioning, and seeing the currently placid, obedient, young girl sitting beside me, it seemed unlikely that she had a serious mental impairment which would lead her to such outbursts. I believed she was in fact frustrated. She could not hear to obey orders and could not speak to ask for certain wants or wishes. How she displayed this was to get angry and throw pots and hence make herself known to the people around her. Using role play, I had the entire community cover their mouths with their hands and attempt to tell me something they wanted. This was a very powerful technique I learnt in my training: to put able bodied individuals into the shoes of those with less abilities as a way to develop empathy for their situation. Whether the role play worked to assist this particular girl I do not know, but it was a situation that moved me from accepting local cultural norms, to considering human rights and using clear, unbiased analytic skills to determine a situation.

Although the above story is extreme, it wasn't unique to India. I faced similar cultural beliefs in the UK. Some people accepted that an individual had a learning disability because of a religious ideal. Or there was the difficult issue of neglect and the idea that the individual had a disability due to a past wrong-doing. These situations made providing rehabilitation services, particularly when administered by a third party (usually a relative or carer), very difficult.

Another difficult situation I encountered in both India and the UK was client expectation of what physiotherapy could deliver. Often you were put on the spot to come up with an answer immediately. In India, this meant being surrounded by the entire village; in the UK, it was family members or some neighbours. Community physiotherapy work often requires a great deal of discussion and negotiation of the roles of all those involved in the rehabilitation of an individual. Realistic expectations should also be discussed from the outset. Many of the clients I saw in India and the UK had long standing, permanent disabilities and an appreciation of the limitations of physiotherapy is important in building a trusting relationship between the physiotherapist, the client and their carers.

Language and simplicity

With the transference of skills and ideas, language and simplicity of ideas play a key role. Although English is widely spoken in India (and is the most spoken language after Hindi) we were faced with many language barriers. Working in rural areas, we were often required to work through an interpreter when visiting clients in their home. In one very rural tribal village, we had a three-way translation occurring between our health worker, a local villager, and ourselves.

With a non-professionally trained translator we were often at the mercy of what they were saying, having no idea what was really being translated. Often a single line of English would be translated for about two minutes. It was obvious that direct translation was not being carried out.

It was also apparent that patience was necessary and that a certain amount of professional courtesy needed to be extended to our Indian counterparts. Often they would surprise us with complex questions they asked the clients and community without our input which they would then translate back to us. In our training of their assessment skills, they showed how they were developing the skills of analysis by questioning clients directly, even if it left us less the wiser for most of the assessment.

Language was a similar barrier in the UK. I was often faced with individuals who did not have English as their first language, or as a result of their disability, could not converse with me. Often it was more difficult to work with an individual who had limited knowledge of English as it was difficult to ascertain how much information they really understood as they were usually too embarrassed to say they did not understand. The techniques of patiently using a translator or gaining information from a carer about my client's functioning were similar in the UK to those I used in India.

Transferring skills and knowledge to those with less training also requires patience and the use of simple language. There is very little place for jargon- when working in the community

in any country. When working for particular individuals in the community, the community is your greatest asset (be they the client, direct carers, local health worker, or neighbour) and respect for their level of education and skill is essential. It is the members of the community who will provide the direct care for your client and as such skills transference needs to be provided in as simple a way as possible.

Flexibility

Finally, one of the most important aspects I found while working in the community in India and the UK was the need to be flexible. Working in different countries, different communities, with different individuals, will throw you different challenges and opportunities. It is how you grasp the opportunities and confront the challenges that will determine if you will be successful or not. Being flexible with one's own expectations of what can be achieved is also essential and will provide a strong foundation for fitting into a community no matter how diverse and different they may appear.

Conclusion

I found strikingly similar approaches in how I carried out my work as a physiotherapist with people with disability in community settings in India and the UK. Working in the community allows you to see your clients in their environment and allows you to really appreciate their situation. Working closely with your multidisciplinary colleagues and developing a working relationship that allows you to share common skills and approaches, and to not be professionally threatened by that, is essential, particularly when working in resource poor areas. Focusing on the whole person, considering their environment, and how they wish to function within it, and involving the community will enable a physiotherapist to more capably provide the most appropriate therapy and advice regardless of where in the world you may be.

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Wheelchair provision in less resourced settings

Kylie Mines, Motivation Australia

Motivation is an international not-for-profit development agency established in the UK in 1991. Motivation Australia established in Australia in 2007. The organisation's mission is to 'enhance the quality of life of people with mobility disabilities'. As we recognise that an appropriate wheelchair is an essential tool to enable people with mobility impairments greater opportunity for independence and an improved quality of life, a major focus of our work is providing appropriate wheelchairs.

The need

At a conservative estimate, 20 million people living in low income countries require a wheelchair and do not have one. The barriers preventing wheelchair users from accessing a wheelchair that meets their needs include financial, physical, lack of rehabilitation and wheelchair services, and lack of choice.

Donated wheelchairs

For many years, the most common approach to wheelchair provision in low income countries has been the donation and distribution of inappropriate orthopaedic style wheelchairs for mass distribution. Such wheelchairs, designed for short term hospital use in a developed country environment, are not suitable for long term wheelchair users living in low income countries where they quickly break down due to outdoor use. Wheelchairs are often handed out without any form of screening or individual assessment putting wheelchair users at risk of physical harm from the development of secondary complications such as pressure ulcers or postural deformity.

World Health Organization guidelines

In recent years there has been increasing recognition of the unique needs of wheelchair users, and the importance of implementing programmes that result in sustainable, appropriate approaches to wheelchair provision. In November 2006 representatives from organisations working in the field of disability and development, including Motivation, came together for a WHO, USAID and the International Society for Prosthetics and Orthotics hosted Wheelchair Consensus Conference. The conference concluded that: 'The number of people who need wheelchairs is so large that all efforts should contribute towards developing long-term sustainable services.'

In August 2008, the WHO launched Guidelines on the Provision of Manual Wheelchairs in Less Resourced Settings. The guidelines, developed through a consensus process, provide

minimum standards and recommendations for three key areas of wheelchair provision: design and production, service provision and skills training of local staff.

Definition of 'an appropriate wheelchair'

The WHO guidelines (WHO 2008:21) have taken the important step of defining what is meant by 'an appropriate wheelchair':

'a wheelchair that meets the user's needs and environmental conditions; provides proper fit and postural support; is safe and durable; is available in the country; and can be obtained and maintained, and services sustained in the country at the most economical and affordable price'.

This definition is crucial in that it recognises the relationship between the user and the product, and the role played by wheelchair services.

Wheelchair design

Motivation believes that wheelchair designs must meet the local conditions and needs of the users. Since 1991, Motivation has designed a range of mobility products including three wheel rural chairs, four wheel fixed frame and cross frame, hand propelled and motor assisted tricycles and supportive seating for children with specialist postural support needs. Motivation designs take into account the user's needs, environment, local materials, safety and durability, affordability and aesthetics.

Wheelchair production and supply

A number of small scale local workshops have been established in low income countries through the work of Motivation and other development organisations, and the efforts of purely local initiatives. Local production has a number of advantages including the skilling of local staff, creation of an income generating workshop and ability of wheelchair users to directly feedback to producers about the design. Wheelchairs produced from locally available materials and using technologies well understood in that location can be readily repaired.

Some of the disadvantages with local production include the difficulty some organisations find in maintaining a production workshop, and maintaining quality. Small scale production workshops are often unable to meet the large demand for wheelchairs.

Building on experience in wheelchair design and production in low income countries, Motivation has initiated the Worldmade Programme which utilises economies of scale available through mass production to produce wheelchairs at a relatively low cost for provision in low income countries. The first chair in the range, a 'rough terrain' three wheel wheelchair is shipped from the factory in a 'kit' to a local wheelchair service, for assembly to size, following assessment of the wheelchair user.

Wheelchair services

The way a wheelchair user receives a wheelchair has a major impact on whether the wheelchair improves the user's quality of life. Wheelchair services are the link between wheelchair users and producers/suppliers and provide the framework to assess individual wheelchair user needs, provide an appropriate wheelchair, instruct and educate wheelchair users and provide ongoing support and referral to other services where appropriate.

The provision of wheelchair services in low income countries, where there are limited resources and a lack of general rehabilitation services, requires careful planning. Motivation works within each country with local partners and relevant Government authorities to identify strategies to develop services for wheelchair provision. Wheelchair services can be successfully integrated with other rehabilitation services including prosthetics and orthotics services and general rehabilitation units. Some aspects of wheelchair provision can be carried out in the community, through a network of community based organisations (for example CBR programmes, community health programmes) supported by a local wheelchair service centre.

Training in wheelchair provision

One of the conclusions of the Wheelchair Consensus Symposium held in Bangalore in 2006 stated 'The number of people who need wheelchairs is so large that all efforts should contribute towards developing long-term sustainable services.'

Short, modular courses can be an effective way of increasing the number of local staff in low income countries who have at least basic knowledge and skills in wheelchair provision.

Motivation has developed a range of short courses including the 'Fit for Life wheelchair prescription course', which runs over 10 days. The target participants are non professionals who may have had limited training in physical rehabilitation. The course covers generic wheelchair assessment to a 'basic' level. It does not cover modifications or complex postural support and does not cover in any depth the specific needs of children. The focus is on providing participants with the skills required to competently carry out the clinical role in each of the key steps in service provision. Wheelchair users are actively involved in assisting throughout practical sessions and illustrated characters are used throughout to illustrate key learning points. Assessment is carried out throughout the course, using a standardised system of competency assessment.

Motivation is working with the WHO on the further development of training packages for wheelchair service provision staff in less resourced settings.

Conclusion

There is a need for greater understanding of the issues associated with wheelchair provision in low income countries — including recognition of the context in which wheelchair users live, the scarcity of resources and lack of rehabilitation professionals and training opportunities for rehabilitation staff to support wheelchair service delivery. However, through the work of Motivation and other organisations, there are appropriate solutions being developed and implemented — including appropriate designs, production and supply options, training tool development and delivery of training. With increased collaboration amongst relevant stakeholders, there are opportunities to make a positive impact on the need for appropriate wheelchairs and wheelchair services.

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Applying for refugee status in Australia: The experience of people with disability

Brooke Andrews, The Onemda Association

Introduction

On Monday, April 2, 2001, Shahrzad Kiane doused himself with petrol and set himself alight on the steps of Parliament House, Canberra. A month and a half later he died as a result of the massive burns.

What statement could be important enough for this individual to believe the only way to get attention was to sacrifice his life? Mr Kiane's daughter with cerebral palsy was being denied an application for refugee status in Australia due to the estimated cost of her disability.

This paper examines the plight of people with disability when applying for refugee status and raises a number of questions: Are there any rights or conventions in place to ensure equal opportunity or are people with disability ostracised and excluded due to their disability?

The purpose of the UN Convention on the Rights of Persons with Disabilities:

is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (UNHCR 2007:Article 1).

Is this Convention, to which Australia is a signatory, being honoured?

Define refugee

The 1951 Convention relating to the Status of Refugees (and its 1967 Protocol), to which Australia and 140 other states are signatories, defines a refugee as:

Any person who owing to a well founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his/her nationality and is unable, or owing to such fear, is unwilling to avail himself/herself of the protection of that country (UNHCR 2007:Article 1).

Modern Australia has been shaped by the resettlement of people from virtually everywhere in the world and Australians have sought to have a say in who can enter and live in their country. These opinions demonstrate those whom we respect and welcome as a member of our community and who can contribute to its worth, to those whom we reject and who are unvalued within our community (Goggin and Newell 2005). Where do applicants with disability fall?

People with disability face many barriers in life. It is estimated by WHO that more than 600 million people live with disability, with 80 per cent living in developing countries (Women's Commission for Refugee Women and Children 2008). Why is it that those most in need remain one of the most neglected, socially isolated and marginalised of all internally displaced people today?

The case of Mr Kiane

Mr Kiane was a Pakistani refugee who had been granted entry into Australia in 1996, he then appealed for his wife and three daughters to join him. His application was denied twice, due to the perceived burden of care of his eight year old daughter with cerebral palsy. He was awaiting the outcome of a third application at the time of his death.

The Commonwealth medical officer who reviewed his application found Mr Kiane's daughter would cost the Australian community \$430,745 for special education, sheltered employment and residential care. Mr Kiane's wife advised the Commonwealth that her daughter's disability was well controlled and that her sister-in-law, an Australian citizen, worked with people with disability and would be able to assist with care (Goggin and Newell 2005).

The Commonwealth Ombudsman engaged in the case highlighted in his report that the Department of Immigration, Multicultural and Indigenous Affairs could look into waiving the girl's health requirements. The Department invited a third application, and indicated the Minister would be sent a request to consider the waiver (ibid).

The application was lodged on September 14, 2000. After three follow-up enquiries by the Ombudsman, the Department advised a delay with the application due to an increase in the projected healthcare costs. Three days after this news, Mr Kiane made his own tragic protest.

Australia's migration policy has always contained provisions relating to health requirements. All people entering Australia need to meet certain health requirements, unless a decision is made, on an individual basis, to waive these constraints (ibid). When the Disability Discrimination Act was passed in 1992 it included an exemption (for immigration) to the Migration Act, Section 52 (MDAA 2008).

Disability discrimination is illegal in Australia, but it can be employed by the Department of Immigration, Multiculturalism and Indigenous Affairs (DIMIA) when dealing with refugee applications from people with disability (ibid). DIMIA use health criteria and specifically the cost to the Australian community and the drain on health and welfare services as cause for rejection of applications for people with disability (Goggin and Newell 2005). The Minister for Immigration can, however, use discretionary powers under Section 417 of the Migration Act to grant refugee status to people with disability (MDAA 2008).

This highlights the fact that a person with a disability is always going to face difficulties when applying for refugee status. Their application cannot even be processed without interventions. In Mr Kiane's case his daughter's cost of care was deemed excessive and thus this family was denied a reunion on Australian shores. His death was a tragic incident, one that should never have occurred. Others may argue that not every application for refugee status can be granted and a line must be drawn somewhere.

In late 2008, Australian media picked up a story of a migrant doctor and his family who were denied permanent residency in Australia because his son has Down Syndrome. Although the father was providing vital services to the Australian community, a Commonwealth medical officer found that the boy represented significant, ongoing costs to Australian tax payers. This decision was upheld by the Migration Review Tribunal (The Age 2008).

Immigration Minister, Chris Evans, overturned the decision, hailing the Moeller families' 'very valuable contribution to their local community' (The Herald Sun 2008). The outcome of this long and worrying time for this family is a positive one, however, this was only because the case was bought before the Minister. If Australia is rejecting applications for residency from doctors and their families based on disability, what hope does a refugee applicant have?

Equal access and disability

The history of the treatment of people with disability is a sad and disappointing one. This group has historically endured marginalisation, as seen in the placement of people with disability in institutions that separate them from family and the wider community. Even in today's society, when these barriers

are meant to have been broken down, people with disability continue to experience oppression and lack of freedom and equality all over the world (Goggin and Newell 2005).

Most Australians may believe and promote the rights of people with disability, but do they act on these beliefs? Is this partly a reason why those with disability who wish to migrate have such difficulty? Not just because of the stringent health requirements but also because Australians are still learning how to best assist those with disability?

If a family apply to migrate to Australia, and one family member is a person with disability, the family face a very difficult choice. If they meet the conditions, families are generally told that all of them, except the person with disability, will be accepted. Families then face the dilemma of whether to leave the person with disability in the home country or whether to appeal the decision. This forced family break-up is extremely contradictory to the family values of the Australian public and the Government (NEDA and MDDA 2005).

The UN Convention on the Rights of the Child, to which Australia is a signatory, maintains that a child has the right to grow up with their family.

Often families will seek asylum in Australia and hope that once here, it will be easier for their child with disability to be granted permission to stay. However, this is often not the case. According to the National Ethnic Disability Alliance (2002), 378 children were residing in detention centers on the Australian mainland, 16 of whom had disability, including cerebral palsy, hearing and vision impairment and an unnamed genetic condition.

This detention contravenes the UN Convention on the Rights of the Child:

Parties recognise that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. (UNHCR 1989: Article 23(1))

The detention of a child with disability clearly does not promote self-reliance or facilitate the child's active participation within the community. The detention of any child promotes segregation and isolation from the wider community.

No child should be detained in an environment which does not meet their support needs (NEDA 2002). However, families wishing to enter Australia as refugees often have no choice due to the stringent health requirements of the refugee application. For people with disability, the only protection they are likely to receive as asylum seekers is a protection visa which ensures no access to Commonwealth financial assistance such as disability support pension or carer's pension (NEDA, 2002).

Conclusion

How can we as a society promote inclusion and dignity for individuals with disability when they are not granted the same rights as others applying for refugee status? People with disability are already marginalised and face numerous barriers.

To reject visa applications on the notion that disability drains Australia's health and welfare system is questionable. Australia needs to ensure its Migration and Refugee Acts honour the UN conventions it has signed.

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Capacity building through disability rights partnerships

Therese Sands, People with Disability Australia

Introduction

People with Disability Australia (PWDA) is a national disability rights and advocacy organisation formed more than 25 years ago. Our primary voting membership is individuals with disability and organisations of people with disability. We also have a large associate membership of people and organisations committed to the disability rights movement. We have a cross-disability focus — membership is open to people with all types of disability. We are governed by a board of directors, drawn from across Australia, all of whom are people with disability. A majority of our staff are also people with disability.

PWDA provides representation and systemic advocacy for people with disability at state (New South Wales), national and international levels. We provide an individual advocacy service for people with disability throughout the state and national disability hotline services, the national abuse and neglect hotline, and the complaints resolution and referral service for people with disability and their associates at national level.

We are part of an international network of disabled people's organisations (DPOs) through Disabled Peoples' International (DPI), and part of the global disability rights movement. We have United Nations Economic and Social Council (UN ECOSOC) consultative status which ensures that we have a strong voice at the UN, both at Asia-Pacific and international levels. We played a significant role in the drafting of the UN Convention on the Rights of Persons with Disabilities (CRPD) at several of the UN Ad Hoc Committee meetings in New York.

PWDA works in partnership with marginalised people with disability in order to build their capacity for self-representation and advocacy. We have a strong focus on capacity-building partnerships with Pacific DPOs and with Pacific networks of women with disability, as well as advocating within the development sector for disability-inclusive development practices.

Our current key partners are the Aboriginal Disability Network (ADN), the Pacific Disability Forum (PDF) and member DPOs of the PDF. We are increasingly developing partnerships with Asia-based DPOs.

Rationale for capacity building

As a DPO, PWDA shares a common history and purpose with DPOs worldwide. We are part of the global disability rights movement that has demanded a voice of our own, the right to

self-determination and full realisation of the human rights of people with disability. This is captured in the slogan, 'nothing about us without us'.

There is a bond and solidarity between DPOs that comes from a lived experience of disability, and recognition of being 'on the same journey'. DPOs worldwide continually work at building their capacity to have a strong voice of and for people with disability, as this is critical to ending the exclusion and stigma that denies people with disability the opportunities for economic, cultural, social and human development, and limits participation in decision making, civil and political life, all of which reinforce a cycle of poverty and disability.¹

PWDA has significant experience in building our own capacity to advocate for the rights of people with disability. Our capacity-building partnerships with DPOs focus on: sharing and building skills, particularly in advocacy and human rights; sharing knowledge; leadership development; organisational development, such as strategic planning; and collaborating on common advocacy activities in the region and internationally.

Importantly, it is through the establishment of our capacity building, or disability rights partnerships, that we strive to consolidate the development and growth of DPOs in order to build the disability rights movement in the Asia Pacific and internationally.

Our capacity-building framework

PWDA uses a human rights approach to development in the context of a social model of disability. We work with people with all types of disability, recognising that it is not an individual's impairment or diagnosis that is problematic, but rather environmental, communication, information and attitudinal barriers. It is these barriers which deny or limit the human rights of people with disability.

Human rights mechanisms provide the context for our capacity-building work. In particular, the rights outlined in international treaties guide and frame our work. The following treaties are of key importance:

- CRPD;
- UN Convention on the Elimination of all forms of Discrimination Against Women; and
- UN Convention of the Rights of the Child.

Together, these treaties outline how civil and political rights and economic, social and cultural rights apply to people with

disability, women and children respectively. The CRPD also articulates a right to development, which is particularly critical for people with disability.

Our work is also guided by the Millennium Development Goals and the recognition that ending poverty cannot be achieved without including people with disability in actions to reach each of the eight goals.

A key UN action plan that frames our capacity building work is the Biwako Millennium Framework for Action (BMF), and its five-year review supplement, the BMF Plus 5. The BMF outlines seven priority areas of action, with the first two specific to capacity building of DPOs and networks of women with disability.

Disability rights partnerships

Although not a development agency, PWDA has a key role to play in the development sector. As a DPO, we use our experience within the disability rights movement and our own organisational capacity-building history to establish a DPO-to-DPO partnership approach to development practice, which we call disability rights partnerships. Our DPO-to-DPO partnerships put the slogan 'nothing about us without us' into practice.

Disability rights partnerships build capacity on three interconnected levels:

1. Individual: skills building and leadership development;
2. DPO: organisational capacity-building activities; and
3. Global: by building the capacity of individual people with disability and DPOs, we build a stronger voice of people with disability in the Asia Pacific, which contributes to a strengthened global disability rights movement.

The key elements we use to achieve this are:

Advocacy and support including:

- responsive support, where possible, for practical assistance with obtaining medical and health aids, and other aids and appliances;

- in line with human rights legislation and principles, providing supports required by people with disability to participate equally in our skills-building programmes or meetings;
- advocating within the development and aid sector for disability-inclusive development;
- lobbying governments and donor organisations about responses to the human rights issues of people with disability;
- campaigning collaboratively with partner DPOs on key human rights issues;
- developing policy on key human rights issues for people with disability; and
- acting as a mentor for advocacy activities.

Partnership and network building including:

- PDF;
- Asian and Pacific DPO networks;
- DPI and its network;
- Australian Disability and Development Consortium (ADDC);
- Australian Human Rights Commission;
- Disability Studies and Research Centre;
- donor and development organisations; and
- ADN.

Knowledge and skills development including:

- governance training;
- strategic planning;
- advocacy action plans;
- constitution development;
- effective advocacy techniques;
- leadership development activities and programmes;
- understanding and applying human rights frameworks; and
- proposal writing and funds seeking.

Note

1. The cycle of poverty and disability is represented in a diagram produced by DFID and available on the ADDC website at www.addc.org.au/disabilitypoverty.html.

Disability and Development Organisations and Networks

1. Networks

Australian Disability and Development Consortium

www.addc.org.au

The Australian Disability and Development Consortium 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 programmes and policies.

Dutch Coalition on Disability and Development (Netherlands)

www.d addedd.nl

Mission is to improve the condition of persons with disabilities by promoting equality of rights, communal responsibility for care, and social integration.

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.

Global Partnership for Disability and Development, World Bank (GPDD)

www.worldbank.org

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.

2. International NGOs with a disability and development focus

Action on Disability and Development (ADD)

www.add.org.uk

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.

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.

Christian Blind Mission 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: 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 programme 2003-2005.

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.

Disabled Peoples' International

www.dpi.org

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.

Economic and Social Commission for Asia and the Pacific (ESCAP)

www.unescap.org

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 focussing on blindness prevention and Australian Indigenous health.

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.

Impact Foundation (UK)

www.impact.org.uk/index.asp

IMPACT is an international programme to prevent and alleviate needless disability. There are 17 Impact Foundation organisations globally.

International Agency for Prevention of Blindness

www.iapb.org/objective

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.org

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 Organization

www.ilo.org/employment/disability

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 deafblind people in the developing world to communicate, connect, interact and flourish

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, counselling 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.

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.

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.usaid.gov.au/disability

The Australian Agency for International Development has a Disability Task Force, has developed a disability strategy to guide the aid programme and is providing funding for disability support programmes 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 Prodigandhi Kallyan Somity (BPKS)

www.bpkabd.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 is 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

jalyneb@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.fnmdp.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 focussing 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

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 disability. 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

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 disability.

Survivor Corps

www.survivorcorps.org/NetCommunity/

Te Toa Matoa Kiribati Disabled Peoples Drama Group

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 Disability Pasifika Network

Sainimili_t@yahoo.com

A Pacific regional network of women with disability. Focuses on advocacy and awareness raising.

Excerpts from the Convention on the Rights of Persons with Disabilities

Article 9 — Accessibility

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:
 - a. Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
 - b. Information, communications and other services, including electronic services and emergency services.
2. States Parties shall also take appropriate measures to:
 - a. Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
 - b. Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
 - c. Provide training for stakeholders on accessibility issues facing persons with disabilities;
 - d. Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;
 - e. Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
 - f. Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
 - g. Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
 - h. Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

Article 21 - Freedom of expression and opinion, and access to information

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

- a. Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;
- b. Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;
- c. Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
- d. Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;
- e. Recognizing and promoting the use of sign languages.

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:
 - (a) Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;
 - (b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;
 - (c) Facilitating cooperation in research and access to scientific and technical knowledge;
 - (d) 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.
2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.

Biwako Millennium Framework for Action Towards an Inclusive, Barrier-free and Rights-based Society for Person with Disabilities in Asia and the Pacific targets:

1. By 2004, Governments, international funding agencies and NGOs should establish policy to support and develop self-help organizations. Governments should take steps to ensure the formation of parents associations at local levels by the year 2005 and federate them at the national level by year 2010
2. By 2005, Governments and civil society organizations should fully include self-help organizations in decision-making processes. Actions for the targets include the participation of persons with disabilities in policy-making, political representations and capacity building
3. By 2005, Governments should ensure anti-discrimination measures, where appropriate, to protect women with disabilities
4. By 2005, self-help organizations adopt policies to promote full representation of women with disabilities.
5. By 2005, women with disabilities should be included in the membership of national mainstream women's associations
6. Children with disabilities will be an integral part of the population targeted by Millennium Development Goal Target 3, which is to ensure that, by 2015, children everywhere, boys and girls alike, will be able to complete a full course of primary schooling.
7. By 2010, at least 75 per cent of children and youth with disabilities of school age will be able to complete a full course of primary schooling
8. By 2012, all infants and young children (0 – 4 years) will have access to and receive community-based early intervention services
9. Governments should ensure detection of childhood disabilities at a very early age
10. By 2012, at least 30 per cent of the signatories (member states) will ratify ILO Convention 159 concerning Vocational Rehabilitation on Employment (Disabled Persons).
11. By 2012, at least 30 per cent of all vocational training programmes in signatory countries will include persons with disabilities
12. By 2010, reliable data on the employment and self-employment rates of persons with disabilities will exist in all countries
13. Governments should adopt and enforce accessibility standards for planning of public facilities, infrastructure and transport, including those in rural/ agricultural contexts
14. Existing public transport systems and all new and renovated public transport systems should be made accessible as soon as practicable
15. All international and regional funding agencies for infrastructure development should include universal and inclusive design concepts in their loan/grant award criteria.
16. By 2005, persons with disabilities should have at least the same rate of access to the

Internet and related services as the rest of citizens in a country of the region

17. By 2004, international organizations should incorporate accessibility standards for persons with disabilities in their international ICT standards
18. Governments should adopt, by 2005, ICT accessibility guidelines for persons with disabilities in their national ICT policies.
19. Governments should develop and coordinate a standardized sign language, finger Braille (tactile sign language), in each country and to disseminate and teach the results through all means, i.e. publications, CD-ROMs, etc

20. Governments should establish a system in each country to train and dispatch sign language interpreters, Braille transcribers, finger Braille interpreters, and human readers and to encourage their employment

21. Governments should halve, between 1990 and 2015, the proportion of persons with disabilities whose income/ consumption is less than one dollar a day. Actions call for Governments to integrate disability dimensions into MDG baseline data collection and analysis, to allocate a certain percentage of the total rural development /poverty alleviation funds towards persons with disabilities.

Disability, Disadvantage and Development in the Pacific and Asia

*Pamela Thomas, The Australian National University and
Neva Wendt, Australian Council for International Development*

The International Conference 'Disability, Disadvantage and Development in the Pacific and Asia' was the first conference of its kind to be held in the Asia Pacific region and marked a growing recognition of the need to incorporate disability concerns into social and economic development research, training, policy and planning.

The conference was held at the National Museum of Australia, Canberra on Monday 29 and Tuesday 30 September and was followed by a one-day Policy and Action Roundtable on Wednesday 1 October 2008 at University House, the Australian National University. The Conference was organised by the Development Studies Network at the Australian National University under the auspices of the Australian Disability and Development Consortium (ADDC) and in collaboration with key ADDC members including the Australian Council for International Development (ACFID), National Disability Services (NDS) and Australia Pacific Islands Disability Support (APIDS). The ADDC brings together Australian disability organisations, Australian overseas aid and development organisations and academic institutions.

Aims and objectives

The aims and objectives of the two events were to provide the opportunity for those Australian, Pacific Island, New Zealand and Asian individuals and organisations involved in disability and development to discuss, network and exchange information on the following themes:

- the inter-relationship between poverty, disadvantage and disability;
- the impact of disability on achieving the Millennium Development Goals (MDGs);
- the relationship between gender, disability and opportunities for inclusion in social and economic development;
- the social impacts of disability, including health, education and information;
- the role of policies, legislation and international conventions;
- the role of development assistance; and
- practical examples of effective capacity building, training, empowerment, livelihood opportunities, early detection and intervention.

The conference provided a timely and valuable opportunity for networking, information exchange and discussion and was very timely, given the Australian Government's new focus within the aid programme on disability and development. It provided the opportunity to discuss issues relevant to the Australian Government's strategy for addressing disability within the overseas aid programme, the detail of which was introduced at the conference (as the culmination of a significant process of consultation in Australia, Asia and the Pacific).

The one-day Policy and Action Roundtable, following the conference, provided the opportunity for the overseas guests from developing countries to give in-depth feedback to the Australian Government on its strategy and how most effectively to undertake its implementation. It also provided the opportunity for delegates to discuss key issues for the future and recommendations.

Delegates

The Conference was attended by 220 people, more than 80 of whom were from developing countries in Asia and the Pacific. Most overseas participants were representatives of disabled people's organisations (DPOs) and many experience first hand what it means to have a disability in a developing country. A number of participants were also from the Australian disability and development sectors (service providers, DPOs, occupational therapists, academics with research interests in disability, development and poverty alleviation and a range of development agencies). The roundtable and brought together 88 people, mostly from DPOs in the Pacific and Asia.

Conference programme

The main theme of the conference was exploration of the inter-relationship between disability, disadvantage and poverty — a relationship that until recently has not been well recognised in development research, policy or practice. It provided the opportunity for review of available research-based evidence on disability and its impact on national and household economies and on people with disability's access to social services. The first day of the conference focused on the current situation in the Pacific and Southeast Asia while the second day focused on ways that communities, DPOs, government and non-government organisations, international and donor agencies could most effectively address the situation.

Key sessions were:

- Disability and the development agenda:
The current situation;
- The economics of disability, disadvantage and development;
- Social implications of disability: Issues of gender and exclusion;
- Development assistance for disability;
- Moving forward: Practical experience in addressing disability and disadvantage in the Pacific and Asia regions;
- Using conventions, policies, legislation and frameworks effectively;
- What works in practice and why: Case studies from the Pacific and Asia:
 - Capacity building, twinning and volunteering;
 - Empowerment, education and access to information;
 - Inclusion and gender equality; and
 - Advocacy and creating awareness.
- The way forward — discussion forum.

The conference was officially opened by the Hon Bob McMullan, Parliamentary Secretary for International Development

Assistance. In his opening address, 'Putting disability on the development assistance agenda', Mr McMullan introduced the Government's disability strategy for the aid programme, the primary goal of which is to improve the quality of life of people with disability. Mr McMullan welcomed the opportunity provided by the conference to hear further from people with disability from Asia and the Pacific, and their Australian partners about how to effectively implement the strategy.

Small facilitated working groups with case studies in four concurrent sessions identified 'What works in practice and why' in Asia and the Pacific. These working groups provided opportunities to hear from a range of speakers from Asia and the Pacific in an open discussion environment that encouraged wide participation.

Key points from conference papers and discussion

Conference papers and discussion focused on the lived experience of people with disability and their practical experience in addressing disability and disadvantage in the region.

1. Disability, disadvantage and development

In a keynote address, the Hon Bob McMullan, Parliamentary Secretary for International Development Assistance, focused on the social and economic disadvantage experienced by people with disability. He stated that 10 per cent of the world's population (or 650 million) has a disability, and 80 per cent of these people live in a developing country. Women and minority groups are among those most excluded. The Asia Pacific region is home to two-thirds of the world's people with disability, a situation that until recently has been given little consideration in development processes.

Mr McMullan introduced the Australian Government's draft disability strategy for overseas development which calls for issues of disability to be integrated into Australia's entire aid programme. The strategy is rights-based, with education, infrastructure and organisational capacity building at its core. Mr McMullan indicated that disability prevention is also included in the strategy because, for example, 75 per cent of blindness is avoidable through treatment or prevention. 'We need to tell people what ratifying the convention means and explain the relationship of disability to poverty,' Mr McMullan said.

In other keynote presentations, Graeme Innes, Australian Human Rights and Disability Discrimination Commissioner and Maria Reina, Executive Director of the Global Partnership of Disability and Development, highlighted the inter-relationship between disability and poverty. Both pointed to the impossibility of meeting the Millennium Development Goals without addressing the social and economic exclusion of people with disability and their denial of human rights.

Maria Reina illustrated the link between disability and poverty in three case studies. This is particularly true for women and young people. The situation is exacerbated by the exclusion of people with disability from education, services and decision making and by the funding difficulties faced by organisations who promote inclusion.

Graeme Innes discussed exclusion and the need for people with disability to be aware of, and able to demand, their human rights. He urged people with disability in the Pacific to familiarise themselves with the UN Convention on the Rights of People with Disability (CRPD), and lobby for their governments to ratify it. In the Pacific region, only Australia, New Zealand and Vanuatu had ratified to date. People with disability in the region are often not aware of the Convention, and advocates were urged to direct awareness-raising efforts to government and the community. Limited understanding about the Convention and human rights means many people with disability lack the tools to lobby their leaders for the policies that affect them. It was noted that a difficulty in the Pacific is that individual human rights perspectives are viewed as incompatible with communal Pacific island social structures.

Key points from the discussion were:

- Disabled People's Organisations (DPOs) must collaborate, not compete for scarce funding;
- too many programmes fail to consult people with disability;
- a core challenge for government is how to organise the strength of people with impairments;
- Pacific countries need to ratify the CRPD; and
- greater cooperation is needed between governments and NGOs.

2. The economics of disability, disadvantage and development

Frederick Miller, Pacific Island Forum Secretariat and Tewai Halatau, Pacific Disability Forum illustrated the economic difficulties faced by people with disability and their families. While recognising that the Millennium Development Goals (MDGs) and the Biwako Millennium Framework (BMF) are key instruments for promoting the rights of people with disability, the MDGs cannot be achieved unless the poverty of people with disability is specifically addressed.

The BMF provides comprehensive guidelines for realising the rights of people with disability, but achieving these aims will involve a collaborative effort of diverse stakeholders.

Three short case studies highlighted reasons for the economic exclusion of people with disability.

- Damian Griffis, Aboriginal Disability Network, stated that accepted rates of disability in indigenous communities are twice that of the

general population, due to:

- lack of access to good quality health care;
 - lack of access to housing and infrastructure;
 - greater exposure to violence and abuse;
 - psychosocial influence of colonisation; and
 - substance abuse.
- Abdus Sattar Dulal, Bangladesh Prodidbandhi Kallyan Somity and Nonoy Concha of the Philippines considered from their experience that an important element of improving the economic inclusion of people with disability involves sharing and partnerships. Suggestions to achieve inclusion included:
- sharing knowledge among other DPOs;
 - developing networks from the bottom up and supporting village-level groups to become formalised into a national network;
 - developing peak bodies to be responsible and accountable; and
 - raising public awareness.

3. Social implications of disability — gender and exclusion

Sainimili Tawake, Women with Disabilities Pasifika Network and Dan Stubbs, Australia Pacific Island Disability Support (APIDS), outlined the results of recent UNDP research into women with disability in the Pacific. Andonia Piau Lynch, Disability Promotion and Advocacy Association, Vanuatu discussed the support women with disability need.

Women with disability face double discrimination, particularly in traditional societies. Limited policy and legislation exists to support the rights of women with disability, with very limited research to date on women with disability in the Pacific region.

Women need information about their rights, empowerment, equal access to education and non-discriminatory services. They also need access to a legal and political system that recognises their rights.

4. Development assistance for disability

In plenary sessions, Laurie Dunn, AusAID and Megan McCoy, NZAID outlined the role of development assistance in supporting and empowering disability organisations and individuals in the Pacific and Asia.

NZAID has been supporting Pacific DPOs for some years and AusAID has recently established a Disability Task Force to develop a disability strategy for the aid programme. The strategy will ensure that disability is firmly entrenched throughout the agency's work. Laurie emphasised that listening to what people with disability in the region had to say was critical to the success of developing the strategy.

(Editor's Note: The Strategy was launched by the Hon Bob McMullan on November 25, 2008. On Australia Day January 27; the AusAID Disability Task Force was presented with an Australia Day Award for its outstanding work).

Development agencies are taking lessons learnt from mainstreaming gender when developing disability policies. They are also examining the strengths and weaknesses of their own organisations, including staff capacity and partnering. Partnerships, especially with people with disability, are seen as central to the process, as is the rights-based approach. There is pressure to work with robust organisations, but time is required to build DPOs to be on par with NGOs.

Key observations on AusAID's and NZAID's disability approaches:

- AusAID's disability strategy process will be a transformative process within the agency;
- a slow rollout of programmes may create frustration;
- empirical data on disability is urgently needed;
- continual sharing of good practices and approaches between AusAID and NZAID is valuable; and
- NZAID and AusAID's recent activities have galvanised development partners into putting more focus on disability.

5. Practical experience in addressing disability in the Pacific and Asia

Based on practical experience in the Pacific and Asia regions, Debra Perry of the International Labour Organization, identified the following key areas for change:

- promote the social model of disability because barriers cause the greatest disadvantages;
- identify champions and disability experts at the local level;
- build appropriate skills to ensure accountability;
- address the particular needs of women;
- address the informal economy opportunities and challenges as this is where most of the job opportunities are;
- stimulate the inclusion of people with disability in skills training programmes;
- identify creative approaches to deal with the most marginalised; and
- strengthen DPOs.

Setariki Macanawai, Pacific Disability Forum (PDF), discussed the coordinated approach now developing in the Pacific through the growth of regional organisations. He suggested that people with disability in the Pacific are the most marginalised members of their communities — 'uncounted and unheard ... their rights to development, full participation and

equality are not upheld.' Lack of awareness and understanding in the community means that people with disability and their families face prejudice, discrimination and rejection, a view shared by government representatives from 12 Pacific Island countries at a UNESCAP meeting in Thailand, 2002.

6. Using conventions, policies, legislation and frameworks effectively

Robyn Hunt, Human Rights Commissioner, New Zealand, Andrew Byrnes, University of New South Wales, and Alastair Wilkinson, UNESCAP, Suva provided practical information on how conventions, legislation, policies and frameworks can be used as effective tools to enforce the rights of people with disability. Robyn stressed that as a crucial starting point, people with disability must be aware of the conventions, policies and legislations which affect them. Governments, DPOs and development organisations must recognise that access to this information is a fundamental human right and it must be provided in accessible formats to people with different disabilities.

Andrew explained that the rule of law was important in promoting inclusion of people with disability. Governments are obliged to share information about laws and policies once they come into effect. There are cost implications for creating accessible information, but it need not be excessive if new media/technology avenues are explored.

Alastair stressed that if disability policy is to have an impact, the process of policy development must be taken to the community and worked on within relevant social and cultural contexts. Collaboration brings people to the centre of policy making.

Summary of key points

- conventions, policies, legislation and frameworks are important tools for encouraging inclusion of people with disability;
- governments are obliged to share information about laws, policies and conventions;
- DPOs play an important role in communicating information to people with disability;
- disability policies must be developed in the community;
- 'nothing about us without us'; and
- information sharing among DPOs is a way of capacity building.

Case studies (four concurrent workshop sessions)

Sixteen case studies around four major themes provided a wide range of practical experience, lessons learned and recommendations for the future. The key outcomes from each session were:

Capacity building, twinning and volunteering

- from small things big things grow — initial email exchange can lead to connections that strengthen DPOs and local NGOs;
- success is contingent on the recognition of the rights of people with disability; and
- regardless of the approach taken, shared goals, mutual respect and shared learnings offer staged progress.

Empowerment, education and access to information

- use all your contacts;
- never miss an opportunity to call the country to task on existing laws;
- if laws don't exist, encourage their development or signing of international ones; and
- share information — lack of access to information is the main issue.

Inclusion and gender equity

- build networks and support one another;
- the Pacific can and will build with the resourcefulness of women;
- communications can be very exclusive with men often acting as gatekeepers;
- challenges of sustainability;
- importance of microfinance;
- women and girls need education to be able to advocate and enjoy their rights;
- share success stories, not just the challenges;
- advocate to families; and
- advocacy is most successful when women with disability are speaking for themselves.

Advocacy and creating awareness

- understand your audience;
- find a champion for your case;
- establish your reputation and credibility;
- build your case — collect information and research;
- monitor your progress; and
- to ensure communication is effective: people must see your performance and hear your message, then they will react.

Summary of the final plenary session, panel discussion and recommendations

Members of the panel were: David Lewis, Christian Blind Mission New Zealand, Setareki Macanawai, PDF, and Sue Salthouse, Women with Disabilities Australia.

An overall theme of presentations in all sessions was the need for cultural change in the attitudes of all societies towards their citizens with disability. Frequent reference was made to the CRPD, and its effectiveness as a tool that can be used in advocacy with governments, organisations and individuals.

Addressing disability in development

'Nothing about us without us' is the slogan of the disability movement. The presence of so many strong, well-qualified and experienced advocates with disability from the Pacific Region and Asia signals that there has already been significant positive change in disability advocacy in the region. People with disability wish to say 'no' to old advocacy paradigms, 'no' to charity models of condescending help, 'no' to medical models which view people as diagnoses rather than as individuals, and 'no' to colonial undertones in how assistance is conceived and delivered.

Many delegates emphasised that people with disability wish to participate as equals in all processes of developing policies and programmes; to be involved in all levels of society from government to NGOs; and to be consulted and given employment in the delivery of programmes and services. In speaking and acting on their own behalf, people with disability are affirming that a correct cultural context appropriate to each country is needed. Delegates reiterated that they wish to nurture collectives, and build capacity of people with disability to speak and act for themselves. A powerful component of many presentations was the personal stories of delegates. Through sharing stories self worth is affirmed and in turn affirmed by others — an essential part of the process of assuming autonomy.

The various UN conventions and frameworks which underpin advocacy and development work were frequently quoted. Delegates wished to further promote the use of these as key tools for developing policies to ensure people with disability live free and independent lives, with their human rights met. Delegates were encouraged to become more familiar with the CRPD, the Convention on the Elimination of (all forms of) Discrimination Against Women (CEDAW), the MDGs and the BMF and to use them irrespective of whether their home nations are signatories, or have ratified.

There is an urgent and fundamental need for adequate support from governments and other sources to provide the realistic means of carrying out development projects by and for people with disability. In this context presentations from NZAID and AusAID were very significant. AusAID's new disability strategy and the consultative process in which it was developed is indicative of a general culture change. People with disability have become a pivotal part of the aid process.

Integrating and mainstreaming disability

If disability is to be incorporated within all development policy and programmes appropriate consultation and input from people with disability is required. A number of presenters talked about the pros and cons of mainstreaming disability into development assistance programmes and referred to the lack of success of gender mainstreaming. Frequent reference was made to the concurrent need for pro-active projects specifically targeted for people with disability. There was general agreement that all policies and programmes need both disability and gender impact assessments to be undertaken before planning and implementation.

There was also considerable discussion about the need for research and data collection to establish baseline information so that improvement can be measured. General Recommendation 18 (1991) of CEDAW justifies the call for all data to be disaggregated by gender, and mainstream data also needs disability analysis.

Collection of data is just one way of identifying successes. It was agreed that qualitative celebration and publicity for successes has helped get messages to the community, and helped to maintain the morale of those working for change.

What, when and how?

Top of the list of desired actions was the need for support for sustained capacity building within DPOs coupled with the need for leadership development and for mentoring in-country and internationally. Networks for exchange of ideas and information are essential. Nationally, leadership needs to come from politicians and governments, where the rights of people with disability can be vocalised at the highest level. There is a need for change to justice systems and legal frameworks, in addition to increased access to education and vocational training.

There is also a great need for action to address the most marginalised segments of the disability sector, including the importance of addressing gender discrimination in tandem with disability discrimination, because if we get it right for women with disability, then we will improve our societies for everyone.

Conference outcomes — anticipated and unanticipated

Anticipated outcomes: The aims of the conference were very successfully achieved. Participants highlighted its importance on a range of fronts: networking, information exchange, exploration of a large range of issues associated with disability and development, identification of opportunities for poverty alleviation through the disability lens, and engagement between a range of potential Australian and developing country partners, as well as the opportunity for very open discussion with

Australian and New Zealand Government officials.

The Policy and Action Roundtable provided significant feedback to AusAID on the Australian Government's draft strategy for disability in the aid programme and especially on effective implementation processes. The draft strategy has now been formally launched as 'Development for All: Towards a disability-inclusive Australian aid program 2009 – 2014'. It was launched by the Hon Bob McMullan on 25 November 2008 where conference participant from the Solomon Islands, Ms Savina Nongebatu, also spoke.

Unanticipated outcomes: As well as anticipated outcomes, several unpredicted outcomes were evident. These included:

- **Practical application of 'inclusion'.** Social interaction during the conference which had been specifically focused on 'inclusion' of a range of DPOs saw the practical application of 'inclusion' during the conference dinner. Entertainment at this event was provided by a group of intellectually disabled musicians in the band 'Rudely Interrupted'. Participants commented that this gave an example to others about putting the principles associated with disability into practice.
- **Practical application through disability and sport connection.** Involvement informally of disabled athletes who had recently returned from the Beijing Paralympics, served too to give a dimension for practical application of 'inclusion' through sport. This interaction highlighted for many of the participants the importance of actively seeking out opportunities (thinking laterally) for including people with disability.
- **Media coverage** of the conference provided an excellent opportunity for many of the overseas participants to get their message across — many programmes that were aired (especially by ABC Radio – Pacific network) were heard back in their home countries. This in itself should assist with advocacy by developing country participants with their own government officials in their home countries.
- **Human Rights Awards for two ISSS-funded participants.** Two of the ISSS participants (Setareki Macanawai from Fiji and Andonia Piau-Lynch from Vanuatu) have recently been recognised regionally through the Regional Rights Resource Team (RRRT)/ Secretariat of the Pacific Community (SPC) Human Rights Award. They were two of four recipients (from a very strong field of 16 nominations) and they received special commendation for their work with disability.

The exposure/profile given to them during the conference, we believe, may well have contributed to this regional award recognition.

- **Women's Networks.** Networking between the Pacific Women's Network for people living with disability and the Australian Women's Disability Network was another unexpected event that spontaneously emerged and has resulted in a partnership arrangement which it is hoped will be long term.
- **Australia Pacific Islands Disability Support (APIDS)** consolidation of work within their Pacific network and further opportunity for coordination of activities through a concentrated block of time for engagement with Pacific Disability Forum (PDF) and its members.
- **New project of DPO capacity strengthening.** A partnership has emerged between the ILO, Australian Business Volunteers (ABV) and the National Disability Services (NDS) forged at the conference and which focuses on capacity strengthening by Australian volunteers located in Asian DPOs.
- **Linkage of the conference with the Australian Leadership Awards – Fellowship (ALAF) Program** (involving 21 Asian and Pacific participants) gave an added dimension (and breadth) to the professional development of this particular group. The opportunities for networking provided by their involvement in

the conference were considerable and the impact of this is immeasurable. During the ALAF programme, several referred to the value of this engagement (although some would have preferred to have had the conference at the end of their one-month of professional development rather than at the beginning).

Future

Contact is being maintained with conference participants and especially with the more than 80 people from developing countries who participated in the Policy and Action Roundtable. These people are interacting with the Australian Disability and Development Consortium (ADDC) network via the google group. As well, several Australian organisations from both the disability and the development sectors are discussing more in-depth engagement through partnerships. For example, the Australia Pacific Islands Disability Support (APIDS) is in close contact with several of the Pacific Island participants to assist with hands-on small-scale capacity support. Similarly close contact is being maintained between People With Disability Australia (PWDA) and Pacific partners who were involved in the Conference. New linkages has been developed between Pacific and Asian partners in a mutually supportive network.

It is expected that this networking, information exchange and relationships built and strengthened during the Conference and associated Roundtable, will be ongoing.

It is envisaged that another Conference (building on relationships and networks) will be held in 2010. At this stage the exact time and place have not been determined.