

Free and Equal:

A Review of NZAID Pacific Regional
Disability Programme for New Zealand
Agency for International Development

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FREE AND EQUAL: The title of this report derives from a number of sources. The first article of the *Universal Declaration of Human Rights* (1948), quoted in NZAID Human Rights Policy Statement, asserts that “All human beings are born free and equal in dignity and rights.” ‘Freedom’ and ‘equality’ also reflect what we have referred to as the twin-track approach in NZAID’s current policy on disability issues, which we have highlighted in this report: addressing inequalities between those who have disabilities and those who do not; and supporting specific initiatives to empower people with disabilities. This, it is argued, is more likely to foster social inclusion, and thus eliminate poverty. Finally, we heard this cry as the aspirations of people with disabilities in the Pacific, voiced in the consultations undertaken for this Review. They deserve no less.

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PART 1: Executive Summary

Seeking to move to a more strategic developmental approach that meets their principles and ways of working to effectively address the needs of people living with disabilities in the region, NZAID commissioned consultants Daniel Stubbs and Garth Nowland-Foreman to undertake a Review of its Pacific Regional Disability Programme. This report documents that Review and gives the Pacific Regional Health Programme a clear, strategic direction for assistance in the area of disabilities for the next 5 years.

Background and Policy Context

First the report gives the background and context for disability issues in the Pacific region (Part 2). Having analysed a wide range of policies, papers and research, Section 2.1 of part 2 focuses on the key contextual documents and the regional developments which have contributed to the recent (tentative) emergence of disability as an issue in the Pacific. These include: extending the *Asia-Pacific Decade of Disabled Persons*, the *Biwako Millennium Framework (BMF)*, adoption of the BMF by Pacific Islands Forum leaders, UN conventions including the proposals for a *Convention on the Rights and Dignity of Persons with Disabilities*, and developments in the collection of disability statistics.

This is followed by some consideration of the relevant NZAID and other New Zealand policy context. In particular: NZAID's health policy, NZAID's Human Rights Statement and the New Zealand Disability Strategy are considered. A useful explanatory tool drawn is from the NZAID Health Policy and used throughout the consultation and research phase of this Review. It is, what we refer to as, the 'theory of change' embedded in NZAID's approach to disability:

“Programmes designed to improve health status and eliminate poverty will be ineffective if they view disability in isolation. A twin track approach, which (a) addresses inequalities between those who have disabilities and those who do not, and (b) supports specific initiatives to empower people with disabilities, is more likely to foster social inclusion, and thus eliminate poverty.”

This 'twin-track approach' approach was readily understood and appreciated in our consultations, and enabled us to focus on key issues of inclusion, equality, empowerment and the barriers to the achievement of these for people with disabilities.

As a way of giving more detail to the extensive work of community based organisations some history is given to enable some understanding of the tasks already undertaken, largely voluntarily in the region. Although only a glimpse of non-government work in the region, Section 2.3 attempts to provide the reader with some recognition that this report builds on the considerable work of many individuals and seeks to provide for a logical extension of that work into the future.

Today, however, despite impressive work at a local level in a number of places across the Pacific, as well as political support at the highest level, there is very little action at a regional level and insufficient support for national and local work for and with people with disabilities (Section 2.4). The report briefly documents this situation before going to the substantive aspects of the Review.

Inclusion International Project (2002-2005)

Part 3 reviews the Inclusion International Pacific Regional Disabilities Project funded by NZAID from 2002 to 2005, considering achievements against each of its four objectives:

- a. Establish a Pacific Disability Network to share information and support people with disabilities in Pacific countries;
- b. Undertake a review of all disability related legislation in Pacific countries;
- c. Undertake needs analyses of people with disabilities in several Pacific Countries
- d. Coordinate a further “Disability in the Pacific Study Meeting”.

We found that *Inclusion International’s* project was very well documented and showed activities outlined in the project document had been completed, with some minor exceptions that were the result of gaps and external constraints (Section 3.6) unforeseeable by *Inclusion International*. Further, the outcomes did not suffer for a lack of any effort on the part of *Inclusion International* (see, for example, Appendix VI). This is especially illustrated by the work undertaken outside the minimum requirements of the contract (Section 3.5). Some lessons learnt from this work are then discussed (Section 3.7).

Key Pacific Regional Disability Issues

In order to better understand the needs of people with disabilities in the region for the future, an environmental scan and a summary of key regional issues, donor involvement and activities in the area of disabilities is provided in Part 4. Most of this information and the related findings are drawn from the interviews and workshops held in four Pacific island countries during June to August 2005 (Appendix I). Although many who have worked in the region may not be surprised by these findings, they do illustrate the magnitude of the task ahead in promoting empowerment and reducing the inequalities experienced by Pacific Islanders with disabilities.

The lack of awareness of even the existence of people with disabilities and negative attitudes towards them was seen as the greatest barrier to equity and empowerment (Section 4.1). Other significant barriers included: lack of physical access to the built environment and lack of practical support for people with disabilities.

With the assistance of *Inclusion International*, and considerable dedicated work by people with disabilities and their supporters, disabled people’s organisations (DPO’s) now exist in a number of Pacific Island countries. Section 4.2 discusses some of the work of DPO’s to reduce the above barriers, the limitations on these organisations and their considerable opportunities for further work.

Throughout this Review process, policy and legislation were regularly identified as the solution to many of the problems confronting people with disabilities. Developments in policies and legislation can articulate the rights and entitlements of people with disabilities. However Section 4.3 illustrates that on their own policies and legislation are insufficient to make a real difference for Pacific Islanders with disabilities. Unimplemented rights-based policies and legislation may do more harm

than good as such documents breed complacency or cynicism, and potentially remain misunderstood.

If resource limitations were inappropriately cited for the lack of practical policy/legislation, this challenge was magnified for the lack of service delivery (Section 4.4). Specialised disability services (where they exist) seem to do more for segregating and hiding people with disabilities than reducing inequality and promoting empowerment. Moreover mainstream services (eg schools, training and open employment) frequently seem to be inaccessible to people with disabilities.

The issues identified in Part 4 of the Report tend to stem largely from a lack of recognition that people with disabilities even exist in Pacific Island countries. The shame of disability and unwillingness to claim rights contributes to the negative attitudes or often paternal approach taken toward people with disabilities - thus limiting their potential and creating a catch-22 situation that keeps people with disabilities marginalised.

Although services and equipment are desperately needed, long term cultural change in the attitude towards, and treatment of, people with disabilities are what is first needed to make all other forms of support appropriate and sustainable.

In summary the Review finds that the key strategic priorities for action at this time in the Pacific for people with disabilities centre around four areas:

- basic awareness raising and advocacy cannot be stressed enough as a high order need which will create the receptive environment required for other change;
- activities supported by the NZAID Pacific Regional Disability Programme and its philosophy must gain leverage over other resources as well, if the ambitious objectives of poverty reduction and social inclusion are to be realised in any meaningful way;
- strong disabled person's organisations (DPOs) at a national level need to be supported to take up regionally and locally identified needs with appropriate local application; and
- support and resources will also be required at a regional level to enable this necessary in-country work to occur.

Where To From Here?

The NZAID funding programme for Disabilities, a sub-programme of their Pacific Regional Health Programme, may provide funds not exceeding NZ\$300,000 per year for the next five years. We have concluded that the most strategic use of these NZAID funds in targeting the above four areas will be built around offering development support and ongoing core assistance to secure and strengthen an effective regional disability organization in the Pacific. Such an organization could be directly involved in awareness raising and advocacy work itself across the Pacific, as well as providing resource material for and supporting the development of strong disabled persons organizations at a country level. One of the specific areas it will need to tackle is the failure of many donor policies and approaches to adequately recognize and help to address the position of people with disabilities in the Pacific.

The Review identified and evaluated the capacity and capability of key indigenous regional agencies (both government and non-government) with a view to finding Pacific-based leadership capable of promoting and inspiring the attitudinal change

required. What is needed at a regional level (Section 5.1) is to promote change and build on the advances already made including advocacy and policy development, promoting and sharing good practice and technical assistance. The considerable specific work required to continue to meet many of the already identified challenges fall under these headings. This would preferably come in the form of partnerships with and supports for Pacific islanders and their organizations.

Inclusion International, through its sponsorship of the Pacific Regional Disability Project and many previous initiative it and related organizations have involved in, has contributed to a solid foundation for disability initiatives in the Pacific. However, the Review concludes that it is timely for the lead agency role on Pacific disability issues to shift to supporting the solid development of an indigenous Pacific organization.

A range of potential indigenous regional disability organizations (Section 5.2) are considered. A focus is placed on who is best placed to promote, facilitate and deliver against these needs. Also important is the philosophy and control of the organization.

The Pacific Disability Forum (PDF) was found to be the organization that was best fit with a pre-determined set of criteria. It is most entrenched in the Pacific in terms of governance and ownership, it is clearly disability focused and capable of the strategic developmental approach sought by NZAID. Sections 5.3, 5.4 and 5.5 discuss PDF, its strengths and weaknesses to ensure that expectations for this new organization are realistic and in line with its developing capacity.

Recommendation 1: NZAID negotiate with PDF to provide core funding as a strategic regional partner in the disability field in the Pacific, to meet agreed strategic objectives and channel funds to country-based disabled people's organizations working on similar objectives.

Because PDF is a developing organization, currently in transition from a regional network to a regional association, emphasis is put on phasing assistance as PDF develops its capacity to fully operate as a Pacific regional disability organisation in its own right.

Recommendation 2: Funding for PDF be negotiated initially at around NZ\$100,000 to implement Stage 2 over a 12 month period, thus establishing it as a regional association able to deliver advocacy, information and capacity building outcomes and represent Pacific Island country disability issues.

Recommendation 3: NZAID subsequently negotiate ongoing partnership funding for PDF core costs of around NZ\$250,000 per year (including around NZ\$50,000 for discrete regional advocacy and capacity-building project/s).

We also propose that small seeding and capacity-building grants be available to assist in the establishment and/or development of selected country-level disability person's organizations in the Pacific.

Recommendation 4: NZAID allocate PDF around NZ\$50,000 per year to provide seeding and capacity building funding to disabled persons' organizations in Pacific Island countries on agreed criteria.

Infrastructure support is proposed to assist PDF as it develops over this critical next phase of its consolidation and development.

Recommendation 5: PDF Executive negotiate supportive auspice arrangements with an appropriate NGO with a view to securing the highest quality auspice arrangement with one of these organizations, during Stage 2.

Recommendation 6: After appointing the Executive Officer a representative of the Executive Committee should be appointed to work with the Executive Officer to contract formal mentoring support from outside of the organization.

It would not be possible for the NZAID Pacific Regional Disability Programme funding alone to meet the considerable needs identified in this report. Leverage is required over other resources, within NZAID and beyond.

In addition we conclude that NZAID itself needs to ensure that on an agency-wide basis, its own policies and plans appropriately recognize and help address the position of people with disabilities in the Pacific (for example, in its Bilateral, Regional and other specific programmes, such as the Voluntary Agencies Support Scheme).

We also propose specific initiatives for an inter-governmental disability focal point in the Pacific and for targeting of child-related funding to support early identification and intervention for children with disabilities.

Recommendation 7: The Pacific Islands Forum Secretariat (PIFS) be supported to create a position of regional focal point for disability, (1) politically through New Zealand's diplomatic relationship with PIFS, and (2) financially through NZAID's financial relationship with PIFS.

Recommendation 8: NZAID review its approach in negotiating bi-lateral programmes (as well as less formal funding windows) in the Pacific (and elsewhere) to ensure it promotes inclusion and reduces inequalities faced by people with disabilities

Recommendation 9: NZAID commit to this strategic approach from 2006 and raise the issue with other regional donors and at OECD DAC and in related development forums with other development partners.

Recommendation 10: NZAID ensure policy and guidelines currently being revised for VASS (and other funding windows) pro-actively promote inclusion of, and reduce inequalities faced by, people with disabilities.

Recommendation 11: NZAID give consideration to current child-focused funding playing a role in supporting early identification and intervention programs for children with disabilities with a view to their continuing access to education.

Recommendation 12: NZAID request the Secretariat of the Pacific Community (SPC) to target disability issues in its technical development work, in particular SPC's Demography Programme, to provide technical advice, training and support for disability data collection by government statisticians and NGO's.

Finally we also propose that in the next year or so funds be made available for various Pacific Island countries to continue and complete disability identification surveys or similar awareness-raising initiatives, and that this report be made available to participants in the Review as soon as possible..

Recommendation 13: Over the next year or so regional disability funds should also be made available to enable the continuation and completion of national disability identification surveys, such as those initiated by Inclusion International, where requested by national coordinating groups or their equivalent.

Recommendation 14 This Report be distributed by NZAID to all who participated in the Review as soon as possible after it is accepted by NZAID.

Appendices

The appendices provide further background and understanding of the Report. In particular, an outline of the methodology is provided in Appendix I, along with details on documents reviewed and referred to (Appendix II), and people and organizations consulted (Appendix III).

Further and more detailed reference information is provided on the *Biwako Millennium Framework* (Appendix IV), on disability questions and data in Pacific Island country censuses (Appendix V), on examples of country impacts of data collection (Appendix VI), and on the 2005 Pacific Regional Workshop on Disability, (Appendix VII)

The detailed Terms of Reference for the Pacific Regional Disabilities Scoping Study and Review is included at Appendix VIII.

PART 2: Background and Context

This Review both looks back to learn and forward to identify strategic next steps to address inequalities between those who have disabilities and those who do not, and empower people with disabilities in the Pacific. In particular it has sought to both (1) consider the work done by *Inclusion International, Asia Pacific* over the four years from 2002-2005 with assistance from the New Zealand Agency for International Development's (NZAID's) Pacific regional disability funding, and (2) assess the best strategic way forward for NZAID's regional disability funding programme in the Pacific beyond 2005. (The full Terms of Reference for the Review are included at Appendix VIII).

In order to undertake this Review a range of information sources were drawn on. Interviews and workshops were held in four countries with key Government officials, NGOs providing disability services, disabled person's organisations and people with disabilities, family members and carers (in Tonga, Fiji, Vanuatu and the Cook Islands). A workshop was also held as part of a four day Pacific regional workshop on disability (1-4 August 2005) which involved representatives from 14 countries across the Pacific (see Appendix VII). These interviews and workshops were the main sources of information for the Review, and findings are discussed throughout Parts 3, 4 and 5 of this Report. The questions and methodologies used in interviews and workshops can be found at Appendix I. A list of workshops and interviews can be found at Appendix III. We also undertook a review of relevant NZAID files, and analysed a wide range of reports and material provided by *Inclusion International, Asia Pacific* and available on the net and from key Pacific Regional agencies (see Appendix II). An overall outline of the methodology for this Review is provided at Appendix I.

Drawing especially on the later sources, this Part provides an overview of the current policy context for disability issues in the Pacific, especially relevant NZAID policies, and the *Biwako Millennium Framework for Action* (BMF). We also consider the recent growth of a disability movement in the Pacific, and current or planned activity by Pacific regional agencies and others on disability issues in the Pacific.

2.1 THE PACIFIC AND GLOBAL POLICY CONTEXT

Asia Pacific Decade of Disabled Persons

In an Issues Paper¹ considered by officials in the lead up to the 2003 Pacific Islands Forum, a number of key regional and global disability initiatives are identified. The Paper outlines that the Asian and Pacific Decade of Disabled Persons, 1993-2002, was proclaimed with a view to giving fresh impetus to the implementation in the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) region of the World Programme of Action concerning Disabled Persons beyond 1992.

¹ United Nations Economic and Social Commission on Asia and the Pacific, Pacific Operations Centre, with assistance from Disabled Persons International Oceania Sub-region Office & Pacific Islands Forum Secretariat (2003) "Disability in the Pacific Issues Paper" Paper for Forum Officials Committee, Pre Forum Session, Auckland, 2003

Thirteen Forum Island countries became signatories to the Proclamation on the Asian and Pacific Decade of Disabled Persons. Some Pacific Island countries that did not sign the Proclamation, such as Papua New Guinea took an active part in some Decade activities and others that did sign took little or no action.

The Asian and Pacific Decade had 12 major policy areas; each with a list of target areas for the development of policies to support full participation and equality of persons with disabilities in Asia and the Pacific. Progress on these policy areas was reviewed by UNESCAP at its meeting of the Special Body on the Pacific in May 2002. This meeting which included representatives from twelve Forum Island countries, agreed (perhaps generously) that overall, many Forum Island countries had made progress in a number of the priority areas, particularly with: national coordinating committees, legislation; information; public awareness; education; prevention of causes of disability; rehabilitation; self-help organizations; and regional cooperation. It was acknowledged that little progress had been made with: accessibility; training and employment; and assistive devices in particular. While one off examples of progress or planned progress can be identified, these have not been widespread, and in some cases have still not been implemented. Where benefits and improvements have been made, the UNESCAP *et al* (2003) Issues Paper concludes these have probably only reached a very small percentage of people with disabilities.

The May 2002 UNESCAP review highlighted the following areas where further progress was necessary:

- coordination and support of services and programmes provided by NGOs and community and self-help organizations;
- legislation to address the rights and needs, including access and equity issues, of people with disabilities;
- updated information for advocacy and for the purposes of the planning and implementation of services for people with disabilities;
- access to the built environment and to appropriate means of communication, especially in schools;
- public awareness-raising targeting many sectors;
- education for children and youth with disabilities who are widely denied this right in Pacific Island countries;
- access to education, training, employment and income-generating activities to alleviate poverty for people with disabilities;
- preventative and early identification services;
- persons with disabilities playing a key role in the formulation of national policy on all issues that affect their lives directly; and
- strengthening national and regional networks of NGOs, regional organizations, UN agencies and other multilateral organizations.

Biwako Millennium Framework for Action

The *Biwako Millennium Framework for Action: Towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific* (2003-2012) was adopted by Governments at the High Level inter-governmental meeting held in Otsu, Japan, in October 2002, to conclude the Asian and Pacific Decade of Disabled Persons. It is designed as a tool for Governments to use to guide their policies, planning and implementation of programmes concerning people with disabilities. As a result it also offers useful leverage for NGOs and others advocating action on these issues, particularly in those countries which have signed up to the *Biwako Millennium Framework*.

At their 2003 meeting in Auckland the Pacific Islands Forum leaders endorsed the *Biwako Millennium Framework* as providing a set of goals and targets for Pacific Island countries to work towards over the next ten years. The leaders also acknowledged that immediate priorities for Pacific governments should be to address policy that will assist the coordination of services and provide a focal point for people with disabilities within government.

The *Biwako Millennium Framework* explicitly incorporated the *Millennium Development Goals*² and their relevant targets to ensure that the concerns of people with disabilities will be an integral part of the *Millennium Development Goals*. The purpose of the *Biwako Millennium Framework* is to promote inclusive, rights-based societies free of barriers for people with disabilities in the region. To achieve this, it identifies seven priority areas for action:

- A Self-help organizations of persons with disabilities and related family and parent associations;
- B Women with disabilities;
- C Early detection, early intervention and education;
- D Training and employment, including self employment;
- E Access to built environment and public transport;
- F Access to information and communications, including information, communication and assistive technologies; and
- G Poverty alleviation through capacity-building, social security and sustainable livelihood programmes

Twenty targets have been set covering all of these priority areas and a range of strategies outlined for Governments to use in order to meet the targets. The mid-term review of progress against each of these seven priority areas in 2007 offers a strategic leverage point to promote equality and empowerment for people with disabilities in the Pacific. More information is provided on the *Biwako Millennium Framework* at Appendix IV.

² http://www.unescap.org/mdgap/about_MDG.htm

Disability as a Human Rights Issue

The UNESCAP *et al* (2003) Issues Paper notes that the concept and understanding of ‘disability’ has undergone a significant shift in focus from being perceived within a ‘charity’ and ‘welfare’ framework to becoming a human rights issue.

“Disability concerns have been included in such international conventions as the Convention on the Rights of the Child (1999), which makes a specific reference to including children with disabilities (Article 2), and states that:

State Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care... ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreational opportunities in a manner conducive to the child’s achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development... (Article 23, paragraph 2).

“The Convention on the Rights of the Child is the only international convention signed and ratified by all Forum Island countries. There are a number of other declarations, which although they may not make specific reference to disability, they make implicit provision for all, for example: the *Jomtien Declaration on Education for All* (1990), and the subsequent *Dakar Framework for Action on Education for All* (2000); the World Summit for Social Development (1995) and the United Nations Millennium Declaration, embodying the *Millennium Development Goals*.

UN Convention on the Rights and Dignity of Persons with Disabilities

The United Nations General Assembly adopted a resolution (56/168) in 2001 on an international convention to promote and protect the rights and dignity of persons with disabilities. Some Pacific-based NGOs have been actively involved in making submissions to the drafting of this proposed convention.³

The *Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities* is currently being negotiated and drafted within the Ad Hoc Committee for the Convention. Reports from the six Ad Hoc committee Sessions held so far indicate that the Convention is formalizing the rights-based approach now adopted on disability issues.

Legislation

Few, if any, countries in the region have passed legislation to address the rights and needs, including access and equity issues of people with disabilities. Cook Islands, Samoa, Solomon Islands and Vanuatu are currently engaged in the preparation of disability policy and have indicated that legislation is being considered.

More extensive legislation has been passed in Fiji since 1994, with protective provisions in the Bill of Rights of the 1997 Constitution, including Equal

³ United Nations Economic and Social Commission on Asia and the Pacific, Pacific Operations Centre, with assistance from Disabled Persons International Oceania Sub-region Office & Pacific Islands Forum Secretariat (2003) “Disability in the Pacific Issues Paper” Paper for Forum Officials Committee, Pre Forum Session, Auckland, 2003

Employment Opportunity. Papua New Guinea passed legislation in 1993, and is planning the passage of a Disability Act. In Palau, mechanisms for inter-agency collaboration provide support for the rights of people with disabilities under the Americans with Disabilities Act, 1990, even though there is no implementing legislation.⁴ More information on disability legislation and policy development in the Pacific is provided in Part 3.2.

Development Planning

The United Nations Statistics Division⁵ notes that the demand for statistics on disability has greatly increased following the *International Year of Disabled Persons* (1981), the adoption of the United Nations *World Programme of Action Concerning Disabled Persons* (1982), and the release of the *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* (1993). The *World Programme of Action* specifically requested the United Nations to develop systems for the regular collection and dissemination of information on disability.

In 2005 the United Nations Statistics Division will initiate a systematic and regular collection of basic statistics on human functioning and disability by introducing a disability statistics questionnaire to the existing Demographic Yearbook data collection system. The United Nations Statistics Division is currently testing the disability questionnaire and developing tabulation and dissemination plans. It also provides a statistical reference and guide to the standards and methods, and collates available national data on functioning and disability.

It has been argued that access to accurate and regularly updated information is vital for advocacy and for the purposes of planning and implementation of services for people with disabilities.⁶ In recent years, twelve Pacific Island countries have generated some census data on disabilities, but it is patchy and definitional problems make it difficult to compare results. More detailed information on collection of official statistics and outcomes of the Inclusion International surveys on disabilities are provided in Part 3.3.

2.2 NZAID POLICY CONTEXT

The above regional activities and policy developments fit well with the NZAID and related New Zealand policy context, especially the NZAID *Health Policy*, within which the Agency's Pacific Disability programme sits. Also relevant is NZAID *Human Rights Policy Statement* and the New Zealand Government's *Disability Strategy*.

The NZAID *Health Policy* was released in 2005 and takes a 'social determinants of health' approach. Therefore NZAID's work in the Pacific considers whole people, their communities and environments rather than seeing a person only in terms of their

⁴ *Ibid.*

⁵ <http://unstats.un.org/unsd/demographic/sconcerns/disability>

⁶ United Nations Economic and Social Commission on Asia and the Pacific, Pacific Operations Centre, with assistance from Disabled Persons International Oceania Sub-region Office & Pacific Islands Forum Secretariat (2003) "Disability in the Pacific Issues Paper" Paper for Forum Officials Committee, Pre Forum Session, Auckland, 2003

illness or deficiency. This is consistent with other contemporary approaches to health and health promotion taken by a range of other organizations working in the field, such as the World Health Organization⁷.

This approach lends itself well to considering health in the context of poverty. NZAID has recognised that poor health causes poverty and poverty causes poor health. Reducing inequality therefore is seen by this policy as a natural prerequisite for promoting (most, if not all forms of) good health.

Most disability advocates become nervous when a disability policy is placed within a health policy. Health has historically taken (and still in most places takes) a diagnostic and medical approach. In contrast, NZAID's policy sees people with disabilities in terms of any inequality and disempowerment they experience. NZAID staff interviewed for this Review demonstrated they are well aware that there may be issues for people with disabilities in all sector (for example, housing, education, employment, income generation, etc) and across sectors (for example, human rights). As the NZAID Health Policy outlines:

“With access to lessons learnt from support for disability-related activities in the Pacific region, an agency focus on human rights and New Zealand’s active contribution to the development of the draft Convention on the Rights of Persons with Disabilities, NZAID is in a position to support and advocate for the active participation of people living with disabilities in public policy dialogue, development and implementation in all areas.

NZAID will seek to raise awareness of the need to approach disabilities from a rights-based framework focusing on equality and empowerment. With this goal in mind, NZAID commits itself, over time, to developing a mainstreaming approach to disability support which will see the needs and aspirations of people living with disabilities integrated across all relevant policies and programmes.”

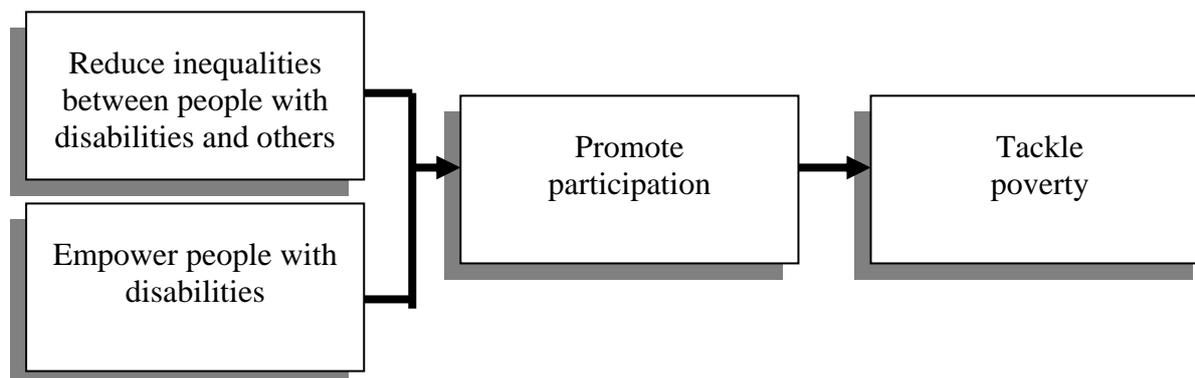
Significantly, any undue emphasis on the need to diagnose disability before taking action is reduced by the NZAID Health Policy's recognition that in any community at least 10 per cent of people will have a disability. Thus the need to *prove* the existence of people with disabilities to NZAID is considered an issue.

The central focus of NZAID is poverty reduction through sustainable and equitable development⁸ Poverty cannot be eliminated while people with disabilities do not participate, and this is recognised by NZAID. During the course of this Review the NZAID's twin track approach of reducing inequality and empowering people with disabilities in order to promote participation and thus reduce their incidence of poverty⁹ was explained and discussed many times. Once explained it was well understood, and was generally strongly supported as a welcome approach.

⁷ See for example the 2005 World Health Report <http://www.who.int/whr/2005/en/index.html> and the Ottawa Charter for Health Promotion http://www.who.int/hpr/NPH/docs/ottawa_charter_hp.pdf.

⁸ NZAID (2002) *Towards A Safe and Just World Free of Poverty: NZAID Policy Statement*, NZAID, Wellington

⁹ NZAID (2005) *Terms of Reference: Review of Pacific Regional Disabilities*



The NZAID Health Policy's approach to disability is also consistent with the *Biwako Millennium Framework* – which is the crucial disability policy agreement in the region. This also fits with the UN's articulation of their move to a rights based approach to disability through the *Convention on the Rights and Dignity of Persons with Disabilities* discussed above.

The NZAID *Human Rights Statement* provides an overarching policy, covering all of NZAID's spheres of poverty reduction objectives in a rights-based approach. The human rights principles espoused by the Statement include: universality and indivisibility, equality and equity, accountability, empowerment, inclusion, non-discrimination and participation. These are all highly pertinent considerations for the position of people with disabilities in the Pacific.

The Statement indicates that NZAID takes seriously its obligations under the range of United Nation conventions supporting social, cultural and political rights; women; children; all races; refugees; labourers and in relation to torture. It is also consistent with the United Nations *Millennium Development Goals*, thus showing how development will be most sustainable where there is equality of opportunity and equality of outcomes.

The Plan of Action sets out the method and timeframe for implementing human rights principles into all of NZAID's work (to be reviewed in 2008). Policies relating to health and disability show that the principles are being taken seriously. As the objectives and actions are at the Agency level, success in the disability field in the Pacific will best be seen by the way in which NZAID works with the Pacific region to promote the rights of people with disabilities in the coming years.

Released in 2001, the *New Zealand Disability Strategy* provides for a long-term process of ensuring New Zealand is an inclusive society for all people with disabilities. It is a cross-government strategy, building on what already has been achieved, but also recognising that many New Zealanders with long-term impairments are unable to reach their potential or participate fully in the community because of barriers they face doing things that most New Zealanders take for granted.

To advance New Zealand towards this vision, the Strategy entails 15 objectives each underpinned by detailed actions. The objectives include:

- awareness raising on disability;
- education, employment and economic independence for people with disabilities;
- mainstream involvement as well as targeted individualised services;
- leadership by people with disabilities; and
- supporting the needs of different races, ages and genders with disabilities.

Crucial to its success now is the reporting process required to be undertaken by relevant government departments. This culminates in the relevant Minister providing a progress report to parliament at the five and ten year points. This could provide a useful model for policy and reporting developments in other countries.

2.3 THE GROWTH OF A DISABILITY MOVEMENT IN THE PACIFIC

“In order to achieve full participation and equality, people with disabilities must play a key role in the formulation of national policy on all issues that affect their lives directly. Self help organizations create public awareness, enable capacity-building, empowerment and strengthen advocacy.”
UNESCAP et al (2003).

Finally, we consider the recent history of the growth of a disability movement in the Pacific. From an outsider’s perspective, the development path that has brought us to today’s *Pacific Disability Forum* (PDF) can be seen to have begun with two separate, but overlapping, groups. One was the *Asian and Pacific Action Committee* (APAC), a sub-committee to IHC (a major disability NGO in New Zealand) and essentially working on behalf of *Inclusion International, Asia Pacific* in the Pacific. The other was the *Oceania Disability Advisory Support Committee* (ODASC), an advisory committee to *Disabled Peoples International (DPI) Oceania*.

Don Wills was Chair of IHC’s APAC from 1979 when it was created during International Year of the Child. The Committee was born out of a recognition that the work that many were doing for IHC and children with disabilities in New Zealand was also needed in the Pacific. The approach was focused on service delivery (although Wills worked mainly as an advocate) as there were few if any services in the countries that Committee members were aware of. For example “the main centre for children with disabilities in Tonga was developed by this group and opened by the Tongan royal family –seeing the creation of APAC” (Interview).

On the service delivery side, New Zealanders with expertise in intellectual disability would be supported to give training in-country. They were seen to give good quality improvements and regular updates in training. Will’s noted in retrospect that “this regular updating was crucial, as we later found to be the case for all aspects of Inclusion’s work in the region.” Wills, as an import-export businessman was able to undertake Inclusion International related work along side his business activities. (This was just one example of *Inclusion International’s* ability to leverage available resources to go a lot further.)

There are similar examples of APAC’s work in other countries. Cook Islanders with disabilities continue to benefit from the Creative Centre resourced by this group. Although before agreeing to the building, APAC attempted to convince the people away from a burdensome building and towards transport and related mechanisms to enable people with disabilities into mainstream employment and education -

indicating their early proactive approach to inclusion. (Years later, this need remained and is somewhat now met by the Red Cross.)

In 1990 a conference on disability was held in Fiji. This was an important gathering. A focus was needed for disability in the Pacific as there was a sense of complacency developing around these issues. Some questioned whether there was a problem or a need at all: "People started thinking that all was ok so we do not need to do anything." The *South Pacific Disability Council* (SPDC) recently emerged after APAC had declined slightly, New focus and vigor was needed for the Pacific based work. The first quarterly issue of *Linking the Pacific* (the newsletter of the SPDC) was released in 1988.

A disability focused Conference in Vanuatu in 1993 saw the further evolution of this Council into the *Pacific Disability Information Network* (PDIN). The presence of the *Inclusion International* World President at this meeting further reinvigorated Pacific Islanders on the issues of intellectual disability. (NB: APAC, SPDC and PDIN did not focus on any specific disability - most Pacific Islanders did not differentiate between disabilities.)

Formal organisations of people with disabilities were formed in Fiji and Solomon Islands in the mid-1990s. Since then, self-help organizations have been formed in Cook Islands (Cook Islands National Disability Council), Samoa (Nuanua o le Alofa), Vanuatu (Disability Promotion and Advocacy Association - DPA) and most recently in Tonga with Naunau o e'Alamite Toga Association (NATA).

In the late 1990's *Inclusion International Asia Pacific* facilitated e- networking of organisations to enable more effective communications between the range of different people and organisations becoming involved in the Pacific disability movement (and PDIN in particular). This was especially important given PDIN's role as an information network, the dearth of information available, and the importance of sharing information and communication capacity across the Pacific.

The *Pacific Disability Development Network* (PDDN) was proposed as the name at a meeting of various countries from across the Pacific in Fiji in 2001. Later came PDDN's involvement in the growth and development of *Pacific Disability Forum*. *Inclusion International's* representatives, JB Munro and Rebecca McCullough continued to be involved in and contributed to the development of this network and its predecessors.

In 2001, representatives from all Pacific-based disabled peoples' organisations (DPO's) met in Port Vila. Representatives came from countries where there were existing DPO's, including Fiji, Solomon's, Australia and New Zealand. . Other people with disabilities came from countries where there were not yet DPO's, including Samoa, PNG, Cook Islands, and Vanuatu. These people gathered in Port Vila for the main purpose of leadership training.

Whilst this group of people with disabilities were in Vanuatu there was a meeting convened by the *Disabled Persons International, Oceania* (DPI Oceania) sub-region Vice Chair (Setareki Macanawai) to discuss the need for an advisory committee to formally support DPI Oceania in its Pacific wide advocacy work. Until this point there had not really been a body to support DPI's work in the Pacific region (nor to support or advise the Pacific Vice Chair on local issues). These country representatives agreed to be a part of this developing regional self advocacy network.

The name of the group was however an issue. DPI, as an international organization of people with disabilities has a strict structure, only allowing organizations solely made up of people with disabilities to gain full affiliation rights. It was believed by the group meeting in Vanuatu that if it was called DPI or the DPI advisory committee, then the non-DPO members could not be involved. There may have also been organizational 'politics' with some organisations who may have wanted to support the committee, but could not (or would not) do so if it was clearly labeled the DPI Advisory Committee. DPI's hard line on a number of disability rights issues over the years had lost it some friends in the international movement.

Further, if it was clearly labeled as a DPI advisory committee, the committee itself and/or its work may need to be ratified by DPI. Nevertheless there needed to be a body to support advocacy of the type done by DPI in the Pacific. Therefore, in recognition that the need for the function was far more important than nomenclature, the *Oceania Disability Advisory Support Committee (ODASC)* was formed.

The 2001 meeting and training in Port Vila had gained important local political support, for example it was opened by the President of Vanuatu. There was a national forum in the park with speakers from various stakeholder groups. The Prime Minister hosted a cocktail party and he publicly acknowledged the issue as important. This was to become a landmark event for people with disabilities in the Pacific. This also planted the seed that ultimately led the Prime Minister of Vanuatu to introduce the subject of disability at the 2002 Pacific Islands Forum, and the subsequent 2003 Forum endorsement of *Biwako Millennium Framework*.

Following the important Port Villa meeting, in the 2001-02 period the DPI Oceania office managed an email list of Pacific disability contacts. This facilitated more effective communication between people with disabilities advocating across the region.

In early 2002 ESCAP and *Inclusion International* representatives met with *Fiji Disabled People's Association*, DPI (Oceania) and other local disability NGO's to further develop strategies to secure disability on the Pacific Island Forum Leaders agenda. Meanwhile, other country representatives had already gone back after the 2001 Port Vila meeting and implemented strategies to lobby their Forum officials to promote disability on the Forum Leaders agenda, as had been foreshadowed in Port Vila by the DPI Vice Chair.

Also discussed at that meeting was the extension of the *Asia-Pacific Decade of Disabled Persons* which was to end in that year (2002). It was agreed that there was a strong need to extend the Decade because little had been achieved in the Pacific to date. Simultaneously, discussions to the same ends were underway in Asia.

After the success of raising the profile of disability issues in Vanuatu and in-country follow-up, the Vanuatu Prime Minister (Edward Natapei), during other business at the 2002 Forum leaders meeting, raised the subject of disability, urging Leaders to address the issue with concern. Leaders agreed that they needed to work in this area and called for it to have it put on the main agenda with a briefing paper at the next meeting (Auckland 2003 Forum). Soon after this, the *Asia-Pacific Decade for Disabled Persons* was extended (2003-2012), and in 2003 the *Biwako Millennium Framework* was developed (see above) and ultimately endorsed by Forum Leaders in Auckland 2003.

Many groups and individuals across the Pacific worked very hard in the background at this time either developing the Issues Paper or advocating to their governments to support the recommendations which were to be presented to the Forum Leaders meeting of 2003.

In December 2002 there was an ODASC meeting funded by the Japanese Nippon Foundation. There had been a Nippon Foundation representative at the regional development meeting in Port Vila (2001), and the ODASC members took the strategic opportunity to discuss the development of the Committee with her at that time. This funder was impressed by the establishment of ODASC and was happy to support its development by backing the next step and funded the 2002 meeting of the Committee in 2002.

A number of others were invited to come to this 2002 meeting: *Inclusion International Asia Pacific*, ACROD (peak body for Australian disability services), Japan International Cooperation Agency (JICA), Pacific Islands Forum Secretariat, UNESCAP Pacific Operations Centre and UNESCAP (Bangkok). The strategic purpose of involving these organisations was to have them share what was happening in their organisations regarding disability in the Pacific and what they might do in the future.

The overall objective for this meeting was to further develop the Committee. This objective was successfully met. There were then organisations represented on the ODASC from all the countries represented at the meeting: Australia, Cook Islands, Fiji, Papua New Guinea, New Zealand, Samoa, Solomon Islands, and Vanuatu.

Presentations from organisations operating in the region illustrated that nothing much was happening for disability across the Pacific, apart from some pockets of work by a select few agencies.

Also at this 2002 meeting the development of the internet Listserv was agreed to and supported by *Inclusion International Asia Pacific* (see Section 4.4). The resourcing of what was to become a valuable communications mechanism was a prescient decision. Initially named the PDDN list, it was soon to become the PDF Listserv.

By the December 2002 ODASC meeting the *Inclusion International*-sponsored PDDN appears to have substantially merged with (or at least become indistinguishable from) the ODASC membership. To *Inclusion International's* credit, they supported and channeled funds for the development of a Listserv as proposed by the ODASC and PDDN membership.

The overall agenda for the 2002 meeting was to form an organisation for people with disabilities in the Pacific, because there was nothing really in existence for and by people with disabilities in the region. The Listserv's establishment was seen as an important step towards this. It was agreed that DPI (Oceania) would take on the moderator role for the List Serve. Also at this meeting the name changed from ODASC to the *Pacific Disability Forum* (PDF) to better reflect the work and representation of the group.

This renaming coincided with the development of the *Asia Pacific Disability Forum*, supported by some Pacific members, to promote the implementation of *Biwako Millennium Framework* in all countries across the Asia-Pacific region. Individuals representing the Pacific (such as JB Munro) in the APDF strongly recognised the need

for a Pacific based disability forum to evaluate what was being done by Pacific governments to implement the *Biwako Millennium Framework*.

This important meeting saw all the people (in particular those affiliated with DPI (Oceania) and *Inclusion International*) supporting each other and working together under the same banner. Clearly all these people had already been working towards the same ends, just in different ways, and now they were operating with together, but importantly still in their own ways as work was required on many fronts.

The group's role had been broadened from an advisory committee to DPI Oceania and an *Inclusion International* committee to a forum for people with disabilities in the Pacific - with the general objective of advocating for the rights and entitlements of all Pacific Islanders with disabilities. Sumasafu Vilsoni of Fiji was appointed as the interim president of PDF from 2002 to 2004.

The December 2003 meeting of PDF in Suva saw the beginning of the development of PDF from a network towards an organisation. It had been agreed that *People With Disabilities Australia* (PWDA) would draft a proposed constitution, and DPI Oceania would develop a draft strategic plan.

The draft constitution and strategic plan were discussed and further developed at the December 2003 meeting in Suva. This meeting was made up of a 3 day *Women with Disabilities Pacific* (WWD Pacific) meeting followed by a 3 day PDF meeting. However travel subsidies were not generally available beyond the funded WWD Pacific participants. The WWD Pacific participants stayed on to be involved in this important PDF development meeting, having an important impact on its inclusive approach. Further, this usefully ironed out some ways of working between WWD Pacific and the broader PDF.

It was agreed that PDF needed another wider meeting to further discuss the constitution and the strategic plan. That meeting occurred in July 2004 in Nadi. This was also preceded by a women's meeting whose participants stayed on.

In July 2004 both documents were presented, though more emphasis was given to the constitution. Both documents were eventually agreed to. It was also agreed that the constitution and thus the organisation be legally registered in Fiji.

It was recognised that even though the strategic plan was a good start, it might need further refining. Even the authors of that strategic plan suggest that further discussions will be required once factors such as income and location are finalised, to make the plan implementation-ready and to enable the further buy-in required for a well supported strategic plan.

In 2004 there was an election and a new Executive Committee was appointed. Fred Miller (Fiji) and Tewai Halatau (Aotearoa/New Zealand) were appointed as co-chairs. The other four Executive Committee members appointed at that meeting were: Sabina Nongabatu (Solomon Islands), Nofo Leanne (Samoa) Heidi Forest (Australia) and Sainimili Tawake Veresoni (Fiji – representing WWD Pacifica Network on the PDF Council).

Since the July 2004 meeting the agreed constitution has not yet been registered in Fiji due to the need to appoint local trustees, as well as the time and money required to do this. Also, the further work required for buy-in and implementation of the strategic plan did not take place between the 2004 and 2005 meetings as such development

work needed to be done through the broader PDF Council. Unfortunately the time and resources to enable this were not yet available.

The future opportunities for PDF are considered in Section 4.2 and Part 5.

2.4 CURRENT REGIONAL ACTIVITIES

“The concept of Pacific regionalism is alive and well in Wellington and Canberra, but often Pacific Island countries are more interested in activities and opportunities outside the region than what neighboring countries are doing.”

This observation from one non-Pacific Islander working in the region typifies some challenges for regional activities. Many Pacific Islanders recognize the needs and opportunities to undertake disability initiatives at a regional level. In particular there are benefits to working with larger numbers, sharing ideas information and resources, tackling common problems and speaking with a single voice. However, cultural differences, costs of travel and communications and the need to ensure that it is something driven from within the Pacific (rather than from Canberra, Wellington or elsewhere) hinder this.

The difficulty of operating at a regional level is further hampered by the fact that most UN bodies, Pacific intergovernmental (CROP)¹⁰ agencies and donors are doing little or nothing for people with disabilities (as discussed in Section 2.4). In fact, the majority of regional work appears to be done far beyond what current resources could reasonably require and augmented by considerable voluntary assistance by people with disabilities and some non-disabled supporters.

However, two regional bodies do stand out for their work in the field – the Pacific Islands Forum Secretariat and UNESCAP Pacific Operations Centre, only in comparison to their regional and international counterparts. This is in comparison to little practical interest, understanding or contribution from other bodies. Even in these two cases the respective officers covering disability issues have a range of other social and cultural issues to service.

The Forum and the Forum Secretariat has supported the development of disability as a regional policy issue. For example, the commitment by the Forum Leaders to disability was first raised by the (then) prime Minister of Vanuatu, then extensive supportive briefing and coordination resulting in a background paper and recommendations to the Forum which gave leaders a tangible outcome in their commitment to the *Biwako Millennium Framework*. Following this, the Secretariat seems to have worked well to support and foster the development of regional

¹⁰ The Council of Regional Organisations in the Pacific (CROP) is an ad-hoc committee composed of the heads of the following Pacific Island intergovernmental organisations, and permanently chaired by the Forum Secretariat. Its purpose is to discuss and coordinate the work-programmes and policies of the different regional agencies to avoid either duplication or gaps in the provision of services to member countries. Its members include: Forum Fisheries Agency; Forum Secretariat; Secretariat of the Pacific Community; South Pacific Regional Environment Programme; South Pacific Applied Geosciences Commission; South Pacific Tourism Organisation; University of the South Pacific; Pacific Islands Development Programme; Fiji School of Medicine; and South Pacific Board for Educational Assessment. <http://www.spc.int/piocean/CROP/spocc.htm>

coordination and cooperation on disability. In particular it has facilitated and supported the emerging *Pacific Disability Forum* as an indigenous, disability focused network for the Pacific. The most recent example of this was the Secretariat's lead role in convening the 2005 Regional Disability Workshop in Nadi (outcomes of the workshop are at Appendix VII).

As we have noted above, a number of people and organizations were involved in bringing about the establishment of disability as an issue on the Forum leaders agenda. The other regional organization which played a significant background supporting role was the UNESCAP Pacific Operations Centre. UNESCAP has also worked closely with the Forum to support take up of this issue in other regional forums such as the Forum Basic Education Action Plan and the 2003 Pacific Island Forum Leaders meeting.

More recently UNESCAP has moved from working mostly at a regional level to the development of country-based disability policies and action plans.

Other regional and international agencies operating in the region do not appear to be taking any major direct initiatives to promote the empowerment of people with disabilities. For example:

- United Nations Development Programme (UNDP) reports that it is waiting for countries and NGO's to raise it as an issue in the Pacific;
- International Labour Office (ILO) is still seeking funding to run a project in several countries which may target legislative and policy reform, training of people with disabilities, and creating employment opportunities;
- United Nations Children's Fund (UNICEF) has decided to focus exclusively on disability prevention as this is "much more cost effective than community based work", although it agrees that early identification and intervention for children with disabilities would be one of the highest impact activities that could be undertaken in the Pacific;
- Secretariat of the Pacific Community (SPC) requires the issue to be brought through the Committee of Representatives of Governments and Administrations (CRGA), although there is scope for them to undertake considerable technical assistance with data collection, awareness raising and education.

Disabled Peoples International (DPI) Oceania is a member of the Council of Regional Organisations in the Pacific (CROP) health and population sub committee. This and other representational work done by DPI Oceania is however unresourced and only supported voluntarily. This reliance on the good will and skills of some individuals is unsustainable. If greater strategic advantage is to be taken of these roles, resources and a network of support need to be established.

The mainstream development aid which is invested in the region also generally does not consider the requirements of people with disabilities. For example, infrastructure development (roads, public buildings, etc) do not necessarily follow local access requirements. Some Pacific Islanders suggest that it would be of great assistance even if the building standards of the donor country were applied, as often development assistance fails to meet the domestic requirements of the donor country.

It is not just capital works programmes that create inaccessibility. The head of one Ministry of Education indicated that PRIDE (the Pacific Regional Initiative for the Delivery of Basic Education) is still not necessarily making education accessible for people with disabilities. Even when additional funds are allocated to basic education under an 'education for all' rubric, it was noted that inclusive education often did not rate sufficient priority to attract any investment.

Community development workers cited many donor application forms which ask what the funds will do for certain groups – “Why not include people with disabilities” as a target group that need to be recognised in any project? It was suggested that this could also apply to funding for large sector-wide approaches to programmes (such as education, health, and infrastructure funding) as well as to small NGO or community-based project funding.

Japan International Cooperation Agency (JICA) has funded some training for people with disabilities in the region (eg through the Asia Pacific Council for Disability), and arranged some overseas volunteers, as has the Nippon Foundation. Other donors in the region have also supported some individual volunteers and funded some in-country support on an ad hoc basis. For example, Australian Agency for International Development (AusAID) has funded human rights training by Fiji Disabled Peoples Association and the Australian High Commission in Tonga funded some useful activities in the development of NATA - the Tongan self advocacy organization for people with disabilities. NZAID has also funded a number of individual in-country projects (see summary table of NZAID Pacific disability related funding below). There are also other agencies providing some funding, training and support to people with disabilities in the region. However, it appears that NZAID is the only donor specifically funding disability related work on a regional level in the Pacific.

NZAID Bilateral Support for Disability Organisations/initiatives

COUNTRY	PROJECT/ORGANISATION	AMOUNT	YEAR
<i>Fiji</i>	Fiji Association of the Deaf for Training Project	F\$4,248	June 2005
	Western DPA for Nursing /Counselling for women with disabilities	\$6,600	for two years (2001/2002)
	FDPA for Leather Craft training project	\$7,780	May 2002
	FDPA printing pamphlets re BMF in Hindi and Fijian.	\$2,500	
	Fiji Association for the Deaf - HOMF grant for PC - to start work on the Dictionary of Fiji Sign Language	\$3,828	
	HOMF grant for books to Hilton Special School.	\$2500	
<i>Tonga</i>	Under Community Development Fund,;two projects of the Tonga Red Cross: 1. Data collection 2. health promotion field worker	T\$20,000 and have transferred the 1st tranche of T\$10,000.00	2004/2005
	<i>Daction</i> - survey (Community Development Fund)	\$17,311.58	Paid on June 2005
<i>Samoa</i>	NGO Support Fund core funds NOLA	NZ\$40,000 pa.	

<i>Kiribati</i>	Radio spots on Disability issues	AUD\$200	Approved 2000
	operational costs for the Disability office	AUD\$2,500	Approved 2002
	transportation costs for disabled students	AUD\$2,500	Approved 2001
	Provision of 2 water tanks to school for disabled	AUD\$2,500	Approved 2003
	repair costs of the school's photocopier machine	AUD\$305	Approved 2004
	Data collection project	AUD\$35,000	Approved 2004
<i>Cook Islands</i>	1)Team to implement the Cook Island disability Policy 2) Creative Centre core funding for 3 years.	\$275,000 over 3 years \$180,000 over 3 years (TBC)	
<i>Pacific Regional</i>	Meeting of the Pacific Forum of Disabled People		2004
	DPI Oceania: training/awareness building workshop for women with disabilities		

Local church based organisations and national societies of the Red Cross undertake a large proportion of the hands-on work to support people with disabilities. It is not clear how much of this work is self funded and what proportion relies on funding from international donors and other funding sources. Organisation interviewed reported and relatively small proportion of their income is allocated from national governments.

PART 3: Inclusion International Project (2002-2005)

The work done by *Inclusion international, Asia-Pacific* on the Pacific Regional Disability Project has been thoroughly documented and well reported. There is therefore no need to reproduce those reports, a number of which are referred to in Appendix II. This Review aims to consider the effectiveness of the work, recognise barriers to its implementation, identify gaps in delivery and discuss what can be learnt from this for future work in the region.

The focus for the project (and in particular the identification of its four objectives) was based on the 1997 NZODA Feasibility Study coordinated by Easterbrook-Smith and others, the 1998 Pacific Regional Disability Study Meeting coordinated by Sumac Consultants, the 2000 Samoa/UNDP Disability Identification Survey coordinated by Sumac Consultants, and especially the outcomes of the 2001 NZODA Regional Disability Study meeting coordinated by *Inclusion International* and IHC New Zealand. *Inclusion International* was commissioned in 2002 by the predecessor of *New Zealand Agency for International Development (NZAID)* to undertake a three year project (2001/02 to 2003/04) at an estimated cost of \$711,150 (subsequently adjusted to an actual \$808,845) to:

- a) establish a *Pacific Disability Information Network* to share information and to provide support for people with disabilities in Pacific countries;
- b) undertake a review of all disability related legislation in Pacific countries in order to assist each country to meet key targets outlined in the *UN Agenda for Action for the Asian and Pacific Decade of Disabled Persons*;
- c) undertake a needs analysis of people with disabilities in a number of Pacific countries in order to put in place mechanisms for further support for individuals with disabilities; and
- d) co-ordinate a further *Disability in the Pacific Study Meeting* to bring together representatives from those countries where the Disability Identification Survey is being used to benefit people with disabilities and their families.

A further \$316,700 was provided in 2004 to enable continuation of each of the first three objectives and some other related activities from July 2004 to June 2005. In reviewing the impact of the Inclusion International project, each of the four principal objectives is considered in turn below.

3.1 LISTSERV

Objective (a) of the Inclusion International project was to: *establish a Pacific Disability Information Network to share information and to provide support for people with disabilities in Pacific countries.*

As the *Pacific Disability Development Network (PDIN)* had been established as a result of the 2001 NZODA Pacific Disability Study Meeting coordinated by Inclusion International, the project was funded to provide: up to ten 'start up' grants to fund purchase of modem, set up costs, six months line rental/Internet service provider

subscription; and honorarium for a Listserv editor, preferably a skilled person from a Pacific country.

The continuation of the project in 2004-05 was to enable the Listserv to be maintained, the hard copy publication of *DPI Oceania News* and the dissemination of the *Women with Disabilities Report* by Sai Tawake, Fiji.

Communication is widely regarded as one of the greatest impediments to organising any form of collaborative activity across the Pacific. It is therefore crucial to continually confront this challenge if people with disabilities and their supporters are going to organize, with the objective of reducing poverty of Pacific Islanders with disabilities.

As illustrated by the history of the development of the *Pacific Disability Forum* (PDF) (see section 2.2), *Inclusion International's* sponsorship of a moderated email listserv was an important turning point for the development of a *Pacific Disability Information Network* to share information and to provide disability-related support. Prior to the creation of the listserv, group email communications were conducted by individuals sending to a large number of recipients. This was problematic with the strict limits on time, volume and speed of internet connections in most Pacific countries. It would also be more difficult to keep up to date, ensuring all recipients were getting all communications.

The hosting of the listserv by *DevZone* (Development Resource Centre, Wellington www.dev-zone.org) was arranged by *Inclusion International*. The agreement to establish the listserv was made at the ODASC meeting of December 2002. That meeting was a precursor to the appointment of the PDF interim Board (see Section 2.2).

Concurrent to PDF's development was the growth of the *Pacific Disability Development Information Network* (PDDIN) lead by *Inclusion International* (see Section 2.2). The limited resources for such networks and the desire to work together eventuated in *Inclusion International's* decision to support the communications network that was to become the *Pacific Disability Forum* (PDF). This was very constructive and showed a crucial and timely pragmatism by *Inclusion International*, which is not always evident with organisational development processes in other contexts.

A key communications barrier for Pacific-wide groups is the up-front and ongoing expense of electronic communications. *Inclusion International* provided much needed assistance here in the form of linking computers to the internet and providing resources to *Disabled Persons International, Oceania*, as the organisation initially allocated the task of list moderator from its office in Suva. Listserv moderation is now mainly done voluntarily by New Zealand-based member, *Vision Pacific Trust*.

A sampling of recent Listserv postings and discussion with a number of subscribers indicates that, what has now become the PDF Listserv has proven very popular and successful for sharing of information, joint advocacy, reducing isolation, sharing ideas and capacity development with others at different points along their development path. Recent examples of the advocacy opportunities supported by the PDF Listserv have been the country-based advocacy on the Pacific Plan, development of a Pacific Plan submission and sharing of opportunities to promote 'inclusive education' as a

part of the 'education for all' programme adopted by the 2005 Regional Meeting of the Ministers of Education in Samoa.

The PDF Listserv now has around 65 subscribers. Its future challenges lie in increasing its use by Pacific Islanders interested in disability issues and the Listserv's role as a vehicle to assist the process of the growth and development of PDF as a network and as an organisation. The limiting factor on growth will continue to be the rate of IT connectivity by Pacific Islanders with disabilities and their organisations.

Although less expensive than telephones, the time and/or volume costs of internet usage are still prohibitive in many Pacific Island countries. This continues to be one of the major barriers to this communication mechanism. The PDF Listserv is sometimes quiet with periods with few or no posts - due to the lack of time, capacity and confidence of subscribers.

It is also worth recognizing that face-to-face communications may be the medium which many Pacific Islanders are more comfortable with. Although electronic forms of communication would be complementary, face to face communication seems to work best. Electronic communications seem to be the least preferred method. This may be partly due to the fact that many Pacific Islanders have a strong oral tradition, which continues today, making different forms of electronic communications less preferred.

In summary, as an interim report on the Project noted in 2004, some of the development impacts from the establishment of the PDF Listserv included:

- Providing opportunities for information and knowledge to be shared that is specific to Pacific people with disabilities;
- Providing development of leadership and management skills for those involved with the network;
- Promoting debate, discussion and some advocacy among the Pacific disability community; and
- Enabling the establishment of the PDF organisation.

3.2 LEGISLATION & POLICY REVIEW

Objective (b) of the Inclusion International project was to: *undertake a review of all disability related legislation in Pacific countries in order to assist each country to meet key targets outlined in the UN Agenda for Action for the Asian and Pacific Decade of Disabled Persons.*

The project was funded to: engage a lawyer knowledgeable about disability related legislation to identify the current status of each country's legislation, especially in regard to the targets of the UNESCAP Agenda for Action for the Asian and Pacific Decade of Disabled Persons; and undertake visits to encourage and advocate for legislative change in each country.

The continuation of the project in 2004-05 was to enable active participation in UNESCAP meetings through the *Thematic Working Group on Disability Concerns* in Bangkok, to further encourage Pacific Island governments to be better informed on disability matters and be assisted to review and up-grade legislation.

A review of existing disability legislation and policy is something which many stakeholders in the Pacific (and further a field) have firmly identified as a priority. It was the subject of a specific recommendation from the first *Disability in the Pacific Study meeting* held in Fiji in 2001.

The need for effective legislation and policy is described in several instances throughout the *Biwako Millennium Framework (BMF)*¹¹. It was also recognised as an area in need of work at the 2003 Pacific Island Forum Leader's meeting in Auckland. Further, the importance of stocktaking, understanding and analysing legislation and policy with respect to disability was regularly identified by people with disabilities, families, service-providers and governments during this Review.

The review of all Pacific Island disability legislation and policy was prepared by Graham McKinstry for Inclusion International. It was first presented at the *Disability in the Pacific Study Meeting* held in Melbourne on 20 September 2002 (see section 3.4). Primarily the research was undertaken at the University of the South Pacific Law Campus, Port Vila in 2002, and the material has been revised from time to time. In 2003, the Forum Secretariat also sought a review of Policy and Legislation on Disability in the Pacific, which McKinstry undertook independently of *Inclusion International*. It drew on much of the material already held and was published as: Graham McKinstry & Penelope Price (2004) *Review of Policy and Legislation on Disability in Pacific Island Countries*, Pacific Islands Forum Secretariat.

In general terms there were two findings. First, although some old (pre-independence) legislation existed, and a variety of international conventions had been adopted, there was no evidence that the limited legislation had been put to effective use. This was the case even in Fiji, where legislation was passed in 1994 to establish a national council to advise Government on disability matters and provide a Government focal point. That office, for example, appeared inactive until after the BMF was adopted.

Second, enacting legislation alone will not change things for Pacific Islanders with disabilities. Such legislation and policy will need to be accompanied by considerable resources in order to have any impact. In recognising the difficulty of mobilising the necessary resources, McKinstry concludes that advocacy, co-operation, and establishment of a central point of contact in Governments are the key ways forward in the Pacific at this stage.

The legislation and policy review material has been presented in a variety of research formats, and has been used and/or discussed at a range of international forums. Notably, these have included:

- *Disability in the Pacific Study Meeting*, Melbourne, 2002;
- *The Osaka Forum*, Osaka, 2002 (a combined forum of Rehabilitation International, Asia and the Pacific, Campaign 2002 to Promote the Asian and Pacific Decade of Disabled Persons and the International Research Meeting on Vocational Rehabilitation¹²);

¹¹ *Biwako Millennium Framework for Action towards a Inclusive, Barrier Free and Rights Based Society for Persons with Disabilities in Asia and the Pacific*, 2002 UNESCAP.

¹² Findings of the Policy and Legislation Review were also tabulated and published in the Osaka Forum publication.

- *UNESCAP High Level Intergovernmental Meeting to Conclude the Asian and Pacific Decade for Disabled Persons*, Otsu City, 2002 (where the Biwako Millennium Framework was agreed);¹³
- *International Labour Office (ILO) Asia Pacific Meeting on Employment of People with Disabilities: The Impact of Legislation*, Bangkok 2003;
- *UNESCAP Expert Group Meeting on an International Convention to protect and Promote the Rights and Dignity of Persons with Disabilities*, Bangkok, 2003; and
- *UNESCAP Regional Workshop towards a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, Bangkok, 2003

Other occasions when this material was shared include the *Inclusion International World Congress* in Melbourne, 2002; the successful advocacy programme in Vanuatu to raise the profile of the *Biwako Millennium Framework* (BMF) in 2002 (see section 2.2); and Civil Society meetings accompanying the *Pacific Island Forum Leaders' Meeting* in Auckland, 2003.

Despite the useful sharing of the outcomes of this sought-after review and analysis at a number of key forums, it has not been much taken up. Many of those organisations and individuals who might have used and shared this work admit to not knowing of its existence, but agree that it would be useful. As a result of the subsequent work undertaken by McKinstry for the Forum Secretariat, a version of the review appears on the Forum Secretariat website at <http://www.forumsec.org.fj/division/DEPD/Social%20Research/PIFS%20Penny%20Price%20doc.pdf> and was presented at the August 2005 Pacific islands Forum Secretariat meeting on disability, following requests for this type of information.

This communication gap may have been because the work was more extensively presented outside of the Pacific itself, even though at prominent Asia Pacific meetings. More likely, however, many individuals, NGO's in general, and disabled peoples' organisations in particular, do not have the time, resources and general capacity to pick up where the policy and legislation review left off. Further, the policy environment in many Pacific Island countries is not receptive to advocacy of this type as considerable support and attitudinal change is required first. These factors are discussed in more detail below (Section 3.6 and Part 4).

Nevertheless the value of this review remains substantial for many countries. While the primary data were collected in 2002, there has been some up-dating since then and, more importantly (though unfortunately) little has changed over the past three years. Its findings therefore are likely to continue to be pertinent until they are picked up by governments and country-based advocates.

In summary, as an interim report on the Project noted in 2004, some of the development impacts from the policy and legislation review included:

- Information and analysis of legislation addressing the human rights of people with disabilities; and

¹³ Note the preamble to the Framework indicates that one of the underlying principles relates to the enactment and enforcement of legislation related to equal opportunities and treatment of people with disabilities.

- Continuing advocacy for people with disabilities at government and international levels.

3.3 DATA COLLECTION

Objective (c) of the Inclusion International project was to: *undertake a needs analysis of people with disabilities in a number of Pacific Countries in order to put in place mechanisms for further support for individuals with disabilities.*

The project was funded initially to operate in five countries (Cook Islands, Kiribati, Samoa, Solomon Islands and Vanuatu) to: coordinate with an in-country advisory group, train in-country partners, collect data using an agreed survey format, and analyse database and develop recommendations in collaboration with in-country partners. This was later expanded to incorporate a number of other Pacific countries, as detailed below.

The continuation of the project in 2004-05 was to enable: further visits to Kiribati and employment of in-country coordinator to enable the survey to be completed; visits and in-country programmes to enable continued implementation of Samoan survey recommendations; visits to Solomon Islands for training and support costs to enable completion of the survey and strategic planning; visits from Samoa representative to Tonga, and employment of in-country coordinator to enable Tongan survey to be started and strategic plan completed; continued phone and email communication with Tuvalu and Tokelau; and visits to Vanuatu for training and support and employment of in-country coordinator to enable pilot to be completed in Tafea and the strategic plan completed for other provinces.

In many Pacific Island countries there is a demand for evidence to demonstrate that people with disabilities exist (preferably in significant numbers), before anything will be done to empower them. This contrasts with the approach in many developed countries where it is recognised that people with disabilities will make up a given (and significant) proportion of the population. It is unclear whether this demand for evidence is mainly driven by Pacific Island governments or at least partly due to requirements of international donors. The evidence of the existence of Pacific Islanders with disabilities could be manifested in several ways. Inclusion International and its partners in a number of Pacific Island countries have and continue to see data collection as the best way of providing this evidence, and thus increasing the visibility of people with disabilities and public awareness of the issue.

Part of the reason data collection became a useful focus of the Inclusion International project is that the methodology utilised by Inclusion International has the potential to meet several purposes at micro-, meso-, and macro- levels:

Micro-level (individual)	Outreach to identify individual people with disabilities and potentially link them up with needed services or resources
Micro-level (individual)	Enable future monitoring or follow-up of identified individuals and the services they are (or are not) receiving
Meso-level (community)	Raise local awareness in the communities where trainers go to recruit and train enumerators and survey households
Meso-level (community)	Identify preventative and community-wide strategies to address issues identified in the survey
Meso-level (community)	Assist in service planning and allocation of services and resources in particular areas
Macro-level (national)	Promote the development of advocacy organizations and networks
Macro-level (national)	Enable policy and programme development and planning from the incidence data produced
Macro-level (national)	Increase political visibility and public awareness of people with disabilities, and barriers to their participation

As discussed below, it is possible to identify examples of each of the above purposes being at least partly achieved in one or more of the countries in which the data collection project was undertaken. This has meant a potentially very significant multiplier effect from the project. However, it has also meant that, with a wide range of potential impacts, not all were able to be thoroughly followed through, and as a result the full potential of the project was not always able to be achieved.

The *Inclusion International* approach can be broadly summarised as:

- 1) Identification of a host organisation in-country, preferred by inclusion to represent (and be run by) people with disabilities and their families;
- 2) Creation of a survey advisory group to apply the methodology, oversee the process and promote the process and outcomes, made up of people with disabilities, family members, service providers and government representatives;
- 3) Identification of potential surveyors, who might be people already working in the field or volunteers;
- 4) Development of a budget to cover all costs, and a plan to attract additional funds where required¹⁴;
- 5) Training of surveyors in relevant locations by Inclusion International;
- 6) Piloting of the survey in a particular region or island, prior to rolling out the survey on a national basis;

¹⁴ The Inclusion International project was not always able to fully fund data collection in a country, and thus additional donors needed to be identified and recruited to support the project in-country.

- 7) A database (based on an Inclusion International model) holds the data, and is preferably located with the host organisation on a computer available to that organisation; and
- 8) Compilation and analysis of the data in conjunction with Inclusion International, and development of a strategy for future action and follow-up.

A number of countries have completed collection of, or are in the process of collecting disability data under the project. At the time of this Review the following progress was identified for eleven countries:

<i>Cook Islands</i>	Completed 2002
<i>Fiji</i>	Undertaking pilot survey in 2005, with a view to seeking government funding for their methodology
<i>Kiribati</i>	Completed 2005
<i>Nuie</i>	Completed 2002
<i>Papua New Guinea</i>	Initial interest expressed (from East Sepik Province), but no further interest from PNG to date
<i>Samoa</i>	Completed for children in 2000 prior to the current project; completed for adults with disabilities in 2002
<i>Solomon</i>	Currently underway, expected to be completed during 2005
<i>Tokelau</i>	Completed 2002
<i>Tonga</i>	Pilot on island of 'Eua completed in 2005, with plans for implementation on an island-by-island basis in 2005 and beyond
<i>Tuvalu</i>	Scoping visit carried out, with a view to future data collection
<i>Vanuatu</i>	Pilot in province of Tafea completed in 2005, now recommending national survey

Data collection is clearly popular among people with disabilities in the Pacific and those working with them: "It is a way of putting disability on the policy and funding agenda". The question must be asked, however, is the demand for data merely the latest excuse by governments for inertia or too many competing demands? Even in those countries where successful data collection has occurred, there is still frustration with governments' inactivity on many fronts (eg Samoa's unfulfilled promise of a disability focal point in government). The fact that those countries doing more for people with disabilities are often those that have collected disability data, may reflect more the corollary of a critical mass of people willing and able to do something, rather than the data collection itself leading to more action on disability issues.

If the same people willing to coordinate data collection focused their energies on advocating on disability issues using internationally agreed incidence data the same result (with respect to government policy) may be achieved. However, it should be acknowledged that undertaking a survey (which may lead to greater awareness etc) is a more tangible and specific focus for people to coalesce around than the general concept of 'advocacy'. Further the range of benefits at micro-, meso-, and macro-levels of undertaking a disability survey can be so significant as to make the process much more worthwhile. In any case, if national governments advise that data is what they need, an appropriate development response can be to facilitate it.

Evidence shows that data collection, followed by strategic advocacy, certainly has the capacity to increase the public visibility of the issue in a way that is frequently accepted as having legitimacy that other (unenumerated claims often do not). And Pacific governments, as much as any around the world frequently only respond to emerging issues when confronted with ‘undeniable’ evidence – especially if it is the public arena. There are some definite indications from this Review that broad programme priorities (for example, in education and health) will only include people with disabilities if there are data to prove their existence and the consequent need. The first step is to use the data as a tool to educate policy makers at all levels. In many instances there is a certain level of awareness, “but decision makers are only just talking about it”. Hard numbers can be a prompt to action, *if* used effectively.

The work done to collect data in a number of Pacific has been nothing short of remarkable. The benefits from this work should not be overlooked. Some of the tangible outcomes already seen from the data collection in a number of different Pacific countries include:

- Training for teachers implemented after finding children with epilepsy not accessing education;
- Cross-sectoral survey advisory committees remaining to tackle other disability issues;
- Visiting specialist teams able to make better use of their time in-country;
- Self advocacy organisations and parent support groups established;
- Disability awareness video/television programmes developed;
- Improved physical access to built environments; and
- Prevention strategies put in place when clusters of disabilities are identified (eg action to prevent high incidence of ear infections);

The approach of going into villages and discussing disability issues has proven to be a successful awareness raising process. Further, where people with disabilities themselves have trained or worked as surveyors this has provided positive role modeling, which has a significantly greater impact beyond the data collection itself.

The data also assists in a more general awareness and education programme for all levels of communities. Most people working in the field recognise that any increase in the visibility of people with disabilities will lead to others ‘coming out’. As it becomes a more visible issue, it is more likely that policy makers and service-providers will increasingly recognise the issue, in turn increasing the incentive for more people to ‘come out’ as having a disability, reinforcing the need for more services and programme inclusion. Thus a virtuous spiral is possible, if the most is able to be made of the data collection opportunity.

Although the primary use of the survey data is as a basis for advocacy to governments and donors, there is not always the capacity in organisations to effectively and strategically compile, analyse and present the data. To minimise cost and enhance strategic relationships, bureaus of statistics are approached to assist with this work. In order to present and promote the data in the most timely, effective and strategic manner, however, it could be useful for these skills to be enhanced within the host organisations.

Mainstream data collection

World Health Organisation (WHO) estimates conservatively at least six hundred million people globally live with disabilities.¹⁵ This is the equivalent to around ten percent of the world's population. Of this total, WHO estimates 80 percent live in low-income countries; most are poor and have limited or no access to basic services, including rehabilitation facilities. The 2001 *New Zealand Disability Survey* (Statistics New Zealand) found that 22.9 percent of the adult population (15 years and over) had a disability of some sort.¹⁶ Of these, 13.3 percent reported having a moderate or severe disability. Disability increases with age, with 39.0 percent of those aged 65 and over having reported a moderate or severe disability. Similarly, the 2003 Australian Bureau of Statistics *Survey of Disability, Ageing and Carers* found 20.0 percent of Australians reported a disability (defined as any limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities).¹⁷ The rate of 'profound or severe core-activity limitation' was 6.3 percent.

Inclusion International originally estimated that at least 5 percent of the Pacific population would have disabilities (*Report to NZODA on Disability in the Pacific*, June 2001). However, they subsequently advised (2004) that the focus of the Inclusion International surveys is more towards those children and adults who have profound, severe or moderate disabilities, which they estimated at 3 percent of the total population. The following chart based on information collated by Inclusion International in 2004 indicates that although such numbers had not yet been identified (most countries were still only at the pilot stage), the numbers identified by the surveys will be significantly more than was previously estimated by Pacific governments and NGOs:

Country and population (based on 2003 NZAID)	Previously reported by Govts/ NGOs, 2001 (%)	Survey results as at 2004 (%)	3% benchmark
Cook Is (21,000)	278 (1.3%)	642 (3.1%)	630
Fiji (868,000)	20,868 (2.4%)	n/a	26,040
Kiribati (95,000)	1,951 (2.1%)	152 (pilot only)	2,850
Niue (2,100)	0	Report most in NZ	63
PNG (5,500,000)	75,978 (1.4%)	n/a	165,000
Samoa (178,000)	1,332 (0.7%)	4,062 (2.2%)	5,340
Solomon Is (500,000)	0	n/a	15,000
Tokelau (1,400)	0	17 (1.2%)	42
Tonga (110,000)	181 (1.6%)	n/a	3,300

¹⁵ <http://www.who.int/nmh/a5817/en/>

¹⁶ <http://www.stats.govt.nz/analytical-reports/disability-counts-2001.htm>

¹⁷ <http://www.abs.gov.au/Ausstats/abs@.nsf/0/c258c88a7aa5a87eca2568a9001393e8?OpenDocument>

Tuvalu (11,000)	n/a	46 (scoping visit)	330
Vanuatu (199,000)	808 (0.4%)	235 (pilot only)	5,970

While it appears that not all people with disabilities are being captured by the survey process, the fact that significant numbers of people with disabilities are being identified (2-3 percent) is highly useful, as it was frequently reported that most policy makers were previously oblivious to the existence of more than a handful of people with disabilities.

Even when undertaken by an official statistical agency, there can be considerable variation in the incidence of disabilities identified. Although there has been some improvement and international standardization in more recent years, the *United Nations Disability Statistics Compendium* (1990) identified variations in national estimates ranging from under one percent to over 20 percent – most of which it ascribes to the different screening methodologies and wide variation in questions asked.¹⁸ In addition, the full costs of an official census or survey are difficult to fund (as discovered in Fiji, discussed below). *Inclusion International's* model of data collection offers a pragmatic way of reducing costs. Any limitations, therefore, need to be seen within the context of Inclusion International having actually undertaken work which other organisations have generally not been willing to do.

The *Inclusion International* methodology might be expected to tend towards at least some under-reporting due to the need to rely on local knowledge of where people with disabilities might be, instead of being able to undertake a full census. Despite the considerable and highly useful training for surveyors, the unwillingness to admit the existence of disability in ones family or community remains.

Therefore, although some statistics may be more broadly defined, sub-set definitions comparable with the Inclusion International survey definition show higher incidence of disability than is currently being identified in Pacific Island countries (for example, 13.3 percent of New Zealanders reporting a severe or moderate disability) and in Australia the narrower 'profound or severe core-activity limitation' was 6.3 percent. Care must therefore be taken in not presenting the Inclusion International findings as final as they will increase as attitudes change and methodologies improve.

There is some benefit in identifying the nature of people's disabilities and where they are located as a form of service outreach. This however is where a pure data collection objective can be corrupted, when it also has 'outreach' objectives. It is possible, given the evidence provided on the 'shame' of disabilities, that Pacific Islanders may be less likely to identify as having a disability if they know that their details (including the nature of their disability) will be held on a database to be shared with other authorities (for example, for follow-up assistance or in the aftermath of a cyclone). On the other hand, some may be more likely to identify themselves or a family member as having a disability, if they believe it will lead to extra services or assistance – rather than purely for statistical purposes.

Although the *Inclusion International* data collection work has been done with the intention of following up to provide assistance, this has not always been possible.

¹⁸ http://unstats.un.org/unsd/publication/seriesy/seriesy_4e.pdf

Even when significant numbers of people with disabilities are known, disability remains a relatively low priority to many government agencies and donors. As a result, follow-up service provision does not always occur. Thus the person with the disability can be left identified, but no better off.

Frequently Inclusion International and several of its partner organisations have been frustrated with their inability to follow up with the necessary services and equipment: *“It will never really be completed. We actually need the action which comes out of the survey to happen (ie the support and advocacy work) to be funded”*.

Some practitioners and field workers suggest that the key benefit of this work is outreach for the provision of services and equipment, rather than the data collection itself. Thus one option for future work of this type could be to better target this ‘outreach’ function as the key objective and any statistics gleaned from the process may be used as evidence for policy and programme advocacy (as a secondary purpose and with the caveat that they do not necessarily represent all people with disabilities, but rather only those identified in this outreach process). With ‘outreach’, then, as the key objective the need for follow up support is more likely to be recognised and thus planned for and budgeted as a part of the process from the beginning.

If this were the case it may be more effective if efforts were directed to ensure disability data collection is undertaken through mainstream statistics agencies. This should ensure necessary rigour, integration with other collections and official status. There are, however, considerable difficulties in this apparently sensible approach. A number of Pacific countries already collect disability related data. From the available census questionnaires,¹⁹ different countries collect disability information in a variety of ways:

- 1) American Samoa, Fiji, Guam, Marshall Islands, Northern Mariana Islands, Samoa, and Solomon Islands ask directly about the existence of disability. This provides the only really useful data, as it asks all respondents if they have a disability, which significantly impairs them in some way.
- 2) Cook Islands, Fiji Islands, Kiribati, Nauru, Niue, Papua New Guinea, Tokelau, Tonga, Tuvalu, and Vanuatu; ask about disability through a (residual) activity status question. This is unhelpful and implies a problematic conception of disability – if one is not in the labour force, one of the optional reasons is because of a disability.
- 3) Federated States of Micronesia and Palau ask how much a person receives in social security payments (including disability payments). This is similarly problematic and not comprehensive, and is even less useful where it aggregates all social security recipients.

The detailed text of questions asked and examples of resulting data is provided in Appendix V. This illustrates the variety and inconsistency of approach to this difficult area of data collection.

The UN *Principles and Recommendations for Population and Housing Censuses* finds that censuses are best used to provide baseline data and may be useful for

¹⁹ Census questionnaires made available by the Demography Programme at the Secretariat of the Pacific Community (SPC).

investigating small-area variations in the prevalence of disability.²⁰ Census data can be utilized for monitoring and evaluation of national programmes. The Principles Report goes on to suggest that only a question focusing on a person's disability (experiences in participating in daily life activities). This approach is supported by the WHO developed set of *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH). ICIDH is a common definition of disability-related issues replacing the body of unstandardized, pejorative terms referring to people with disability with more precise, objective and internationally recognized terminology. As can be seen by Appendix V, these developments have not yet made it to the Pacific causing disability data collection and related policy/programme development to suffer.

The UN *Principles and Recommendations for Population and Housing Censuses* also finds that collecting data on more detailed dimensions of disability should be done through surveys and not population census. Reasons for this include the need for detailed understanding of disability and medical matters.

Very few countries ask disability related questions as part of their official survey processes. For example, the 2006 Fiji Labour Force Survey will ask all respondents a well developed question regarding the incidence, nature and impact of disability. The contents of other Pacific Island country surveys were not available at the time of writing this report. Advice suggests that few if any labour force or household survey's, outside Fiji, include questions on disability, despite the potential effectiveness of this approach.

It is difficult to have any disability questions asked on surveys and or a census. Any questions outside of the core demographic data are very few and the space is highly sort after. Statistical agencies aim to keep the surveys short (one page) and manageable to ensure a higher response rate. Limited resources and the costs involved in enumerators covering all remote areas means that surveys are infrequent. Many ministries, research bodies and some NGO's compete for questions to be included.

The potential of the questions producing useful data also plays a large role in the decision whether to include a question. This was born out in Fiji where the 1996 census included an appropriate disability question only to illicit 3,000 positive responses (0.3 percent of the population), later adjusted to 12,000(1.4 percent of population). The Fiji Bureau of Statistics is now under some pressure not to include a disability question in the 2006 census, in part due to the poor quality of the data yielded from the previous census.

One of the main causes of low response rates is the cultural attitudes toward disability. There is significant shame about disability in the Pacific. Families are frequently unwilling to admit to a family member with disabilities for a range of reasons. Some believe that they have dishonoured God and a child with a disability is their punishment. Some women believe that they did something wrong during

²⁰ UN Department of Economic and Social Affairs Statistics Division, *Principles and Recommendations for Population and Housing Censuses (Revision 1)*, Statistical Papers Series M No. 67/Rev.1, united nations, 92-6.

pregnancy and this is their punishment. Some people with disabilities believe they did something wrong in a past life.

If disability information is going to be collected as part of mainstream data collection, enumerator training will be necessary. There is some suggestion that mainstream enumerators sometimes made the decision not to ask a disability question. Effective supervision and training will be required to ensure that enumerators understand the need to ask (despite their own conceptions) and how to ask it in such a way that families and individuals are willing to divulge this difficult and confronting information.

In summary, as an interim report on the Project noted in 2004, some of the general development impacts from the Inclusion International data collection included:

- *Partnership and local ownership*: Inclusion International has worked in partnership with organizations in each country right from the beginning stages of the data collection, and has worked at the pace of local partners. This has led to a strong sense of local ownership. Where there has been insufficient local interest or support the data collection has not proceeded.
- *Reduction of poverty*: People with disabilities are frequently marginalized, often without opportunities for education, appropriate health care, income, meaningful work, and many other basic human rights. The surveys have helped identify individuals and their unmet needs so that specific strategies could be developed to address them. A number of specific initiatives in several countries (see Appendix xx) can be traced to conduct of these surveys and analysis of its data, for example more teachers trained to teach children with disabilities (and as a result more children with disabilities attending school), increased public awareness resulting in offers of employment to people with disabilities, and strengthening of organizations of people with disabilities able to advocate for human rights of their members.
- *Capacity building*: The survey process can be used to promote cooperation and collaboration among a wide range of stakeholders. These stakeholders involved have the opportunity to learn, develop or practice skills to organise, document, develop strategic plans, recruit and hire, train the trainers, analyse data, etc.

Examples of specific development impacts of the data collection on a country by country basis are included in Appendix VI. In addition, as survey results are analysed and used as a tool for advocacy, there is great potential over time to change attitudes, public policy, access to services and opportunities, and the allocation of resources. As with all data however, care should be taken in how it is presented and used.

3.4 MELBOURNE MEETING

Objective (d) of the Inclusion International project was to: *Coordinate a further "Disability in the Pacific Study Meeting" to bring together representatives from those countries where the Disability Identification Survey is being used to benefit people with disabilities and their families.*

The project was funded to: plan, organize, facilitate and report on a second Disability in the Pacific Study meeting in 2002.

Following the first *Disability in the Pacific Study Meeting* in Fiji in 2001, Inclusion International recognised the need to bring people together again to discuss progress on goals identified in Fiji, as well as to share information on current initiatives, and develop skills and networks. As the Inclusion International World Congress was to be convened in September 2002 in Melbourne, the opportunity was taken to precede this with the Pacific meeting. This meeting successfully brought together a large number of people dedicated to empowerment and equality of people with disabilities from the Pacific.

Importantly, this meeting served to focus and motivate people on the issue of disability in the Pacific. The Pacific legislation and policy review was presented. Possible advocacy approaches were discussed. Pacific delegates took part in the international meeting: learning about experiences elsewhere, finding similarities and building alliances. In general, the meeting built capacity for ongoing in-country work.

The Melbourne meeting was also one important catalyst for ongoing regional activity. Some lament the fact that these meetings do not regularly occur, as they could be used strategically to precede the Forum Leaders' Meeting each year. Pacific disability focused meetings, however, do occur now, centred around the development of the *Pacific Disability Forum* (PDF). Opportunities however do exist for PDF related meetings to be used more strategically.

The Melbourne meeting was clearly successful in terms of its stated goals of information sharing, reporting progress on Inclusion International's other three project objectives (see Sections 3.1, 3.2 and 3.3 above), skills development and development of recommendations for further work. It also had other very positive benefits which should not be overlooked when considering the need for future meetings of this type. Due to the *invisibility* of disability in many Pacific island countries, people with disabilities and their supporters (who are working to empower people with disabilities and reduce inequality) experience isolation and sometimes marginalization or a reduced status. Linking with others helps them recognise that they are part of a much bigger and very important struggle. This considerable, albeit intangible, benefit of bringing such people regularly together should not be underestimated.

3.5 OTHER INCLUSION WORK

Because of the nature of the organization and the people implementing the Inclusion International project, the work undertaken did not simply stop where the project objectives did. There are numerous examples of assistance provided or facilitated by Inclusion International using its skilled people, networks, and resources which would not have been available otherwise. Reported examples include:

- assistance in preparation of funding submissions and accessing funds;
- organisation development assistance and training;
- advocacy training (for example, partnering with local organisations as a watchdog on public policy);
- supporting the representation of Pacific women with disabilities at the 7th Meeting of Commonwealth Ministers Responsible for Women's Affairs, Nadi, 2004; and

- drawing on their international linkages to assist with the application of the Millennium Development Goals to outcomes specifically for people with disabilities.

The *Inclusion International* project also often linked Pacific organizations and people with disabilities with specific people, services or assistance. For example, an interim report on the Project noted in 2004 that a significant amount of equipment had been donated and shipped to various countries as follows: 38 wheelchairs, 17 specialised buggies, 22 walking frames, 35 white canes, 20+ pairs of crutches, 30 pairs of reading glasses, 20 talking watches/clocks, and a wide range of school equipment. *Inclusion International* was able to access free equipment from *Enable NZ*, which, with occupational therapist advice and appropriate modifications, can be adapted for individuals' needs.

In general, *Inclusion International* is seen in the Pacific as one of the few international organisations willing to not only identify what is needed, but actually 'get their hands dirty' and get directly involved in helping address needs. Several people identified that other organisations may come in and identify the needs, but often did not really assist in doing anything about them.

3.6 GAPS AND BARRIERS

Due to the pioneering nature of much of the *Inclusion International* work there were many barriers and gaps which emerged which were unforeseeable and/or out of the control of those undertaking the work.

The cost of travel and communications has limited the effectiveness of some network and development processes. Although this is a well known feature of working in the Pacific, its full cost was unable to be covered by the *Inclusion* project.

Although the approach of undertaking needs analyses through disabled persons' organisations was an important and necessary part of the work, the capacity of such organisations is often restricted. This may have limited the extent to which disabled persons' organisations could attract resources, carry the work forward and follow up on the outcomes, without additional support.

It might be considered that the time taken for the project to fully develop was slower than expected. The original three-year project did indeed need to be extended, a further 12 months, and there are still tasks (particularly in further possible data collection activities) not completed in that time. Some countries have still not effectively 'come on board' with the project, and it could appear that other aspects of the project were slow to 'take off'. If anything, however, this is an error of overly ambitious expectations, rather than faulty implementation. The project implementation appears to have effectively adapted to a 'Pacific pace', enabling adequate time for the development of local involvement and ownership. As a result considerable development impacts have been documented across the Pacific in a relatively under-developed and marginalized field, in a few short years, and with relatively modest funding.

Another factor which may have slowed down the process of *Inclusion International's* work was the speed with which NZAID funds are provided. NZAID did not provide funds in advance of project execution, requiring other reserves to be drawn on. On

some occasions confirmation of project continuation took months, causing delays and uncertainties in Pacific Island countries.

The Fiji data collection project proposed quite a different process to that developed by Inclusion International, making it significantly more expensive. The fundamental difference was Fiji's desire to employ enumerators specifically for the data collection task and train them. This would likely result in a more rigorous survey method and more reliable results. The cost however was considerably more than the Inclusion International methodology provided for (current estimates for the Fiji data collection methodology is FJ\$500,000). Unable to resource such a methodology, Inclusion International has bowed out of the Fiji data collection. Therefore, although there may have been some perceived personality differences and differences of opinion, the reason for the impasse relating to this specific section of work was an important difference in approach and available funds.

The greatest barrier facing all who wish to conduct disability advocacy and support is best described as the 'catch 22' of disability visibility. People with disabilities are frequently physically hidden away in the Pacific and therefore policy makers do not consider them in any of their decision making. As a result of the lack of policies and programmes, very few people with disabilities can become part of the community to make disability a more visible issue. Nor do they have much incentive to do so in an environment where stigma and shame is feared. Therefore disability remains invisible to the whole community including policy makers – who are unwilling to do anything for a group that are not perceived to exist in any significant numbers. It should be noted that the data collection project offered great potential to begin to break this vicious cycle, and begin to turn it into a virtuous cycle where increased visibility and awareness leads to improvements in policies and programmes, which in turn enables increased participation and further visibility, etc, etc.

3.7 LEARNINGS FOR FUTURE WORK

Mainly due to the lack of any disability focal point in the Pacific there is a lack of connection between some of the work occurring around the Pacific. This may also be due to a lack of capacity and resources in country-based and regional organisations to make the connections. The review of disability legislation and policy has been widely regarded as an important analysis, but it has seen low utilization, both by NGOs for advocacy work and by governments to assist in focusing their own legislative and policy agendas. For example, the UN ESCAP Pacific Operations Centre has, for some years, been working with interested governments to develop disability policies which aim to meet the requirements of the BMF on a local basis. Neither Inclusion International nor ESCAP seemed to be fully aware of, nor able to take full advantage of each other's work in these highly complementary areas. Future work would be assisted by a regional coordinating point.

Future data collection work will be necessary in the Pacific. There are many specific lessons for data collection from the Inclusion International project, and these are well documented in many of the country reports provided on the project. The overall objective, however, will also need to be clearer. If advocacy organisations require data to call on governments to provide, increase and improve services and access, then this may be better served by funding to significantly augment mainstream data collection processes (censuses or surveys). Augmentation may include specific training for enumerators, development of appropriate questions and extensions to

existing survey, as well as specific support to disability organizations on how to analyse and make use of the data as an advocacy tool. If the objective is outreach to link individual people with disabilities better with services and resources, then fully funding the Inclusion International process, specifically including the follow up linkages will be important. It is possible for any activity to have multiple spin-offs, but it is important to be clear on its primary purpose, and ensure the design fits that purpose (see Section 3.3).

Following the data collection work there was considerable need identified for follow-up support, not all of which was met. Future projects of this type will be assisted by sufficient continuity of funding to ensure that the outreach work (previously done under the heading: *data collection*) is followed by the necessary support. Without such support the good will developed by the data collection may be lost.

Some other important specific learnings for future outreach/data collection include:

- A widely representative and cross-sectoral advisory committee is critical;
- It works best with a local survey coordinator (preferably paid);
- It is important to make good use of local community support and involvement;
- Geography, weather (rainy season), timing, politics, language differences and transport logistics can make a big difference and underline the importance of being locally driven;
- It need advance community relations and processes for getting local communities on side (eg village meetings, mini-disability awareness workshops, etc);
- It is important to keep government on side and informed of developments (eg Kiribati survey results were launched in parliament in May 2005);
- Action plans may indicate where local communities require help in analysis and reporting;
- Successful engagement with local communities needs more time in-country by the external expert than originally planned, to develop effective relationships and trust; and
- Traditional and religious belief systems about disability are an issue in many countries, and the committee and field workers need to both work with and challenge these beliefs.

If information collected as part of the outreach/data collection process is to be used for advocacy, some accommodation will need to be made for analysing and interpreting the data. Following the analysis, a strategy of publicising the findings needs to be planned and embarked on. This needs to be seen as an integral part of the process, otherwise it risks becoming the weak link in the project's impact. This might include presentations to governments and NGOs, national and international media,²¹ letters to government, ministerial meetings and public advocacy for general awareness raising. Wadsworth (1997) recommends the quarter:quarter:quarter:quarter rule in planning community research – by which she means we should expect to spend about a quarter of our time on planning the research and gathering the necessary people, finances and other resources; about a quarter of our time on data collection; about a

²¹ Most data collection processes gained some local media notoriety, Vanuatu's data collection process gained regional media attention: *Vanuatu: Hard to Learn if Hard of Hearing*, The Independent, Monday 4 July 2005 <http://www.news.vu/en/living/education/050704-Vanuatu-Society-for-Disabled-People.shtml>

quarter of our time on collation, analysis and understanding the results; and about a quarter of our time on identifying the recommendations, disseminating the results and strategizing about its implementation. Most new researchers, Wadsworth contends, focus excessively on the second quarter of data collection, usually to the detriment of the other three quarters.

Strategic follow up is also needed for the legislation and policy review. This review was recognised by Pacific Islanders as a pre-requisite to changing or developing necessary legislation and policy. Therefore the inactivity after its completion not only suggests that *Inclusion International* may not have sufficiently promoted its availability, but also that it was not made readily available in an easily accessible form for some of the potential users, and that disabled persons' organisations may not have sufficient capacity or resources to pick up such a document in the form it was produced and use it as an effective advocacy tool. (The capacity of disabled persons' organizations is discussed further in Section 4.2)

Advocacy capacity, together with infrastructure and other resource capacity, is also required to ensure that the potential of the PDF list is maximised. As it will be difficult to convene more than one regional meeting per year and relatively few people will be able to be resourced to attend this, the accessibility of other communication mechanisms will be very important in maximising the benefits of regional meetings and the effective maintenance of communication and networking across the Pacific (discussed in Sections 3.4 and 5.1).

Ongoing regional meetings, at least on an annual basis, will be necessary to maintain the momentum, reduce isolation and complement country-based advocacy through regional advocacy and support. Attendees will need to share information and learnings from these meetings in their own countries due to the limits on the numbers who can attend. Thus effective post-meeting processes will need to be considered and resourced where required. Also, due to the considerable costs of such meetings, the strategic benefits of where, when and with whom participants meet, will need to be maximised. The Fiji and Melbourne Study Meetings may owe some of their success to their independence from other processes, which can be contrasted (to different extents) with later PDF-related meetings, some of which had to be held with observers and in conjunction with other processes. (This is discussed further in Section 5.4).

Therefore the quality and sustainability of disabled persons' organisations is a key determining factor for future work. This includes the quality and capacity of leadership within those organisations.

Given the barriers and unforeseen difficulties and the modest funding provided, the successes and achievements of the *Inclusion International* project have been considerable. A key learning from this is that funds have been well leveraged to absolutely maximise the benefit of every dollar, draw on a wide range of volunteers (from New Zealand and Pacific Island countries) and draw on the good will from a wide range of relationships. Personalities and individuals have played a large role in making this work. Therefore any future work in the Pacific would benefit from an ongoing key strategic relationship with *Inclusion International*, and the ability to draw on its networks and experience, as required.

Following on from the groundwork established by this project, it is likely that a key part of the next step will be for a Pacific-based and owned organisation to pick up the role of Pacific regional focus for the disability advocacy, support and promotion

work. This next step would not have been possible without the work to date of Inclusion International and of some key New Zealanders and Pacific Islanders who assisted in bringing the issue of disability in the Pacific to this point in its development. In particular this report must reflect the debt of gratitude expressed by many to JB Munro (*Inclusion International Asia Pacific* Regional Coordinator, former Chief Executive & International Officer of *IHC New Zealand*, and chair for several years of the *South Pacific Disability Council* – forerunner of the *Pacific Disability Development Network*), who over many years has had an ongoing commitment to disability issues in the Pacific, and has played a leading and persistent role in the raising its profile both in the Pacific and with NZAID. Mention must also be made of the high regard expressed for the skills and personal qualities of the project coordinator, Rebekah McCullough, and of the many others (paid and unpaid) who contributed to the successes of the Regional Disability Project.

PART 4: Key Pacific Regional Disability issues

In 2003 UN ESCAP prepared a report on the *Asia Pacific Decade of Disabled Persons*²². Chapter II, “Developing Role Models and Resources: Self Determination in the Pacific” reports on the current state of disability issues in the Pacific. Unfortunately, this Review confirms that very little has changed since then:

“Disability services were introduced to the Pacific between the 1960s and 1980s. This saw the establishment of numerous single and cross-disability non-governmental organizations in the Pacific sub-region. The year 1981 was named the International Year of Disabled Persons and Disabled Peoples International (DPI) was formed in the same year. Despite these promising initiatives, awareness of the disability movement and self-help organizations of persons with disabilities has remained minimal in the Pacific, particularly in the smaller developing island nations.

“Traditionally, disability organizations have focused on delivery of services and been managed by non-disabled persons, adopting the view that persons with disabilities must be cared for, protected and segregated. Persons with disabilities were regarded as recipients of goodwill and unable to make their own choices or determine their own destiny.

“Another hurdle in the self-determination of people with disabilities is culture, perceptions and attitudes. These attitudes can act as barriers to the participation of persons with disabilities in affairs that concern them, especially at decision/policy-making levels. The strong extended family system in most countries in the Pacific encourages family members to look after their own sick or less fortunate relatives. The association of a disabling condition with ancestral curse, parental misdeeds, witchcraft, shame and fear keeps persons with disabilities isolated, neglected, dependent and poor. Furthermore, the struggling economies of these island nations also inhibit government attention to the presence, needs and concerns of their disabled population. The disabled population is a minority group in most cases and their needs are outweighed by the national priorities and agenda.

“Further, the ability of self-help organizations to campaign for the rights and needs of the disabled to be put higher on the national agenda is hampered by lack of coordination between the many self-help groups, and their often limited focus and resources.

“The challenge to persons with disabilities in this sub-region is to work towards gaining greater recognition and support for their involvement in decisions and activities that affect their lives. This involvement can be within their local communities, national governments or even management of disability organizations. This involvement is essential if they want to play a more active and leading role in affairs that concern them. This task can only be accomplished if people with disabilities are given equal treatment and

²² UN ESCAP (2003) *Focus on Ability, Celebrate Diversity: Highlights of the Asia Pacific Decade of Disabled Persons, 1993-2002*, Social Policy Paper No. 13, 2003 (ST/ESCAP/2291), ESCAP, Bangkok

opportunity, and are empowered, motivated and equipped with relevant information, skills and experience.”

NZAID has indicated (*Draft Health Policy Statement, 2005*) that it seeks “to raise awareness of the need to approach disabilities from a rights-based framework focusing on equality and empowerment.” In particular, it is argued that poverty will not be eliminated unless people with disabilities are able to participate in society, and that this in turn will require a ‘twin track’ approach, which both (a) addresses inequalities between those who have disabilities and those who do not, and (b) supports specific initiatives to empower people with disabilities²³. This is also consistent with the approach 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*, which was endorsed by Pacific Island Leaders at the Auckland Forum meeting, 2003 as the framework for government action and civil society cooperation in the Pacific (see Section 2.1).

This NZAID Review found a range of issues for people with disabilities, their families and organisations operating in the region. These provide a crucial context for any future regional activity aimed at empowering people with disabilities, and reducing the inequalities they experience on a daily basis. First we examine some of the barriers to equity and empowerment identified by respondents. Then we look at issues for disabled persons’ organizations, with the current state of policy and legislation, and with service provision for people with disabilities in the Pacific.

4.1 BARRIERS TO EQUITY AND EMPOWERMENT

There are numerous barriers which disempower and increase the inequalities experienced by Pacific Islanders with disabilities. Some of the more notable barriers identified in this review are discussed here to give further context for the challenges ahead.

Awareness, Attitudes and Exclusion

There is a low level of awareness of the existence, needs and aspirations of people with disabilities at village, public, bureaucratic, political and service provider levels. This is partly due to the cultural attitudes held by many Pacific Islanders (discussed in Section 3.7 above). It is exacerbated by the lack of services and support provided for people with disabilities. These observations were made by numerous people interviewed for this Review, both in NGOs and government agencies, and were most strongly reflected in the comments made by people with disabilities themselves.

We were advised that, within government, disability is rarely if ever discussed as a policy or funding need, particularly by senior executives. This only tends to change if there is a person or section in government responsible for disability issues and that person has sufficient seniority and/or respect to put the issue on the bureaucratic agenda as well as have it recognized as an issue amongst the range of other policy and programme areas competing for attention and limited funds.

There is significant work to be done to educate communities on disability. As one participant observed, “People still need to be convinced that there is nothing wrong

²³ NZAID (2005) *Terms of Reference: Review of Pacific Regional Disabilities*

with disability.” Reports of taunting and ridiculing suggest that the cultural responses to disability are passed down to young people as well. Pacific Islanders with disabilities reported that their societies generally do not accept nor understand disability; people are frequently judged only by their disability (ignoring many abilities); they are rarely listened to the same as non-disabled people; and are actively discriminated against. These negative attitudes and lack of understanding continue to be the greatest barriers for the full participation of people with disabilities in the Pacific.

Often the discrimination is inadvertent. We heard of a “low awareness of the potential of people with disabilities”. Therefore people with disabilities have tended to remain an untapped social and economic resource for Pacific communities.

While families can offer much protection, care and support for family members with disabilities, the Review also heard that the flip side of this can mean that families, too, frequently perpetuate negative attitudes²⁴. Whatsoever these negative attitudes appear too often to then be accepted by people with disabilities themselves. Many of the same attitudes experienced by people with disabilities in the general community are experienced within the family. In particular there is often a “concentration on people’s limitations”. These attitudes are often informed by the shame and guilt which family members feel about the existence of disability, and which can be transferred to the wider family of a person with disabilities. For example we heard that many other opportunities, such as chiefly and land rights, as well as other traditional rights maintained and transmitted through families and clans are also withheld from people with disabilities – though this may not necessarily be universal in all communities. Nevertheless, this indicates how pervasive the barriers are that people with disabilities face.

As a result of their own, or others’, negative experiences, some Pacific Islanders with disabilities advocate for no role for the family in the lives and aspirations of people with disabilities. However, it is important to remember that in most Pacific communities the family plays a key nurturing and developmental role. A more sustainable response may be to see the family as the first and most important point of awareness raising. It also suggests that families may need to be supported in their caring and support roles, especially for children with disabilities. The issue of service provision and support is discussed further below.

Probably the most poignant examples of the low regard with which people with disabilities are held were the reports of physical and sexual abuse of women and girls with disabilities, which this Review heard. Women and girls with disabilities report that they feel they are seen as easier targets. (These views were received in workshops facilitated and attended only by women and girls with disabilities, enabling this and other gender-sensitive issues to be aired more openly).

Many people with disabilities appear to be denied any opportunities for education, recreation and employment. Most of the opportunities that are available appear to be segregated and frequently of a lower standard. This can result in apparent demand for segregated services (if that is all people are aware of), or of gratitude for whatever is

²⁴ This phenomena is by no means restricted to Pacific nations. A recent survey in New Zealand identified that the single biggest self-identified source of discrimination for people with experience of a mental illness was their family members (Mental Health Foundation, 2003).

provided. However, the process of segregating people with disabilities in education, recreation, employment and other fields causes a long term limitation on those people's ability to reach their potential (beyond that pre-determined for them) in society. Any mainstream position people with disabilities may wish to take up is limited by their life experience of segregation. In particular, and sometimes despite the best efforts of dedicated individuals involved, the segregation often means that people with disabilities, for example, do not receive the same level of education nor are pushed as hard (eg qualifications are not recognized, or are not taught in English). For some this is experienced as self-fulfilling "low expectations of society". As one organization identified, "the best thing is for people with disabilities not to wait, but to get involved in what non-disabled people are doing."

Part of the barrier, however, is the attitudes and self-awareness of people with disabilities themselves. They are no less the products of their societies, than non-disabled people and share many of their attitudes and assumptions. 'Rights' are not necessarily something which most Pacific Islanders identify with, but people with disabilities have learnt to see themselves, often, as having less rights than non-disabled people. This is very disempowering and will require long-term development work in terms of self esteem, confidence building and human rights training for people with disabilities.²⁵

As in many countries around the world, sporting prowess is frequently highly valued in Pacific Island countries. This is one practical entry point to increasing awareness of the capabilities of people with disabilities. Often, however, sports for people with disabilities are attached to institutions which are seen negatively by the community (because of their association with disabilities). Opportunities exist to link disabled sports to mainstream sporting organizations to increase understanding and inclusion. Where this has been undertaken, there appear to be examples of some successful outcomes.

Increasingly, there are people with disabilities and those working with them, aware that inclusion of people with disabilities in all parts of society is also good for the rest of the community. In particular, we heard (albeit still only from a few) an understanding that it is "good for young people's future" to live, study and work with the full mix of society, including people with disabilities.

In general however, the changes in attitudes and awareness required to promote equity for people with disabilities will involve cultural change. A long-term approach therefore needs to be taken in this area of development.

Physical Access

Streetscapes, buildings (public and private) homes and roads are often inaccessible for people with mobility disabilities, (such as physical disabilities, blind, or vision impaired). This is often the case even for new buildings. It also remains a problem for far too many buildings funded and built by overseas donors. There are usually no accessible toilets in public places. This too contributes to the inability of people with

²⁵ Fiji Disabled Persons Association is currently undertaking a human rights project to have people with disabilities train other people with disabilities on their human rights, which may be worth adapting elsewhere.

disabilities to readily interact in the community and therefore also conspires against their visibility as a part of society.

Although retrofitting is more expensive than building in accessibility in the first instance, some basic retrofitting is being demanded by many people with disabilities in order to merely go about their lives, such as gain access to shops, post offices and even in one case gain access to a 'special' school, which was inaccessible. Some disability self advocacy groups have been successful in having some access improvements made as access to the built environment is often the most obvious first step to community access. For new buildings, it can begin with basic planning regulations, including enforcement of regulations in the few cases where they do exist.

Lack of Support for People with Disabilities

Most people with disabilities in the Pacific need the most basic equipment, services and interventions. Examples of people with physical disabilities having to crawl or people with intellectual disabilities left homeless after the death of elderly parents are readily provided. Although these needs may be met by close and supportive village communities, the culture and attitude toward disability also hinders this.

In most Pacific Island countries there is no capacity in remote areas to correctly fit and maintain basic equipment such as wheelchairs, prostheses, crutches, magnifiers, etc. Life in most villages is hard on equipment like wheelchairs so the provision of such equipment is not sustainable without maintenance. This is contrasted with some limited fitting and maintaining capacity in most main hospitals, in capitals and main cities.

Lack of access to basic communications technology can provide serious barriers to people depending on their disability type. Again, this is particularly the case in rural and remote villages and islands where people with disabilities can suffer more profound isolation than their non-disabled peers. Because even telephones are seen as a luxury for most in remote villages and outer islands, people with disabilities are very unlikely to gain access to most forms of communications technology.

The poverty experienced by Pacific Islanders with disabilities creates a double disadvantage for most people with disabilities. Even those *able* to work are usually not in employment, for the range of educational and attitudinal reasons discussed above. If there is a form of government income support, it is easily taken up by the barest essentials for living, leaving nothing to cover the extra (transport, communications or support) costs of someone's disability. To alleviate this some disabled people's organisations have identified income generation projects as an important way of promoting financial independence for people with disabilities.

The position people with disabilities are placed in by not enjoying access to work (in either the formal or informal sector) has complexities beyond their own economic well-being. The guilt carried (including by women due to their inability to contribute to the family in the home in the same way as others) creates considerable stress. The inability to access transport or transport oneself creates extra costs or demands. If someone with a disability requires help in or outside the home then this will add to the perception of burden with which he/she is held, because someone else is stopped from working.

There is little early identification of disabilities conducted throughout the Islands. The Inclusion International project was the first to have done this in many instances. The lack of early identification is a source of considerable frustration to many working in the field, as early identification of disabilities, followed up by even moderate assistance, would have considerable impact. Instead, we heard that many children and young people drop out of school as a result of easily corrected or supported sight or hearing impairments. Others who may best be described as slow learners become classified as having a more profound level of intellectual disability due to their lack of education.

Even where disabilities are identified, the services and resources that do exist are severely limited, and vary widely in quality. This creates barriers for many people with disabilities because of the ‘charitable’ approach sometimes taken. That is, it is assumed that any service for people with disabilities is a good thing, and implying that they should be grateful. In fact some services may be better *not* provided, where they are more likely to disempower people with disabilities, and potentially exacerbate impairments. Issues in service delivery are discussed further below (Section 4.4).

While some systemic advocacy exists with the development of (mostly unfunded) self advocacy organizations (referred to here as disabled Peoples organizations - DPO’s), very little individual advocacy exists. This means that many people with disabilities cannot be assured access to the rights they are entitled to. The issues for disabled persons organisations are further discussed below (section 4.2).

The lack of policies and legislation on which to base advocacy is also problematic. Most Pacific Island countries lack a policy and legislative base for the rights and entitlements of people with disabilities, despite all Pacific governments having committed to the *Biwako Millennium Framework*. This is often an indication of the lack of full and practical government support for the issue, but local and regional developments in this area can also operate to help motivate and support government action on disability issues. Policy and legislative developments are discussed further below (section 4.3).

4.2 DISABLED PEOPLE’S ORGANISATIONS (DPO’S)

The United Nations Economic and Social Commission for Asia and the Pacific identify²⁶:

“The Biwako Millennium Framework states clearly that persons with disabilities are the most qualified and best equipped to support, inform and advocate for themselves and other persons with disabilities. Their input into the proper design and implementation of policy, legislation and strategies will ensure their full participation in social, economic, cultural and political life and enable them to contribute fully to the development of their communities. Communities which encourage this process will in turn be enriched. The targets of the Biwako Millennium Framework demand support for the

²⁶ UN ESCAP (2003) *Focus on Ability, Celebrate Diversity: Highlights of the Asia Pacific Decade of Disabled Persons, 1993-2002*, Social Policy Paper No. 13, 2003 (ST/ESCAP/2291), ESCAP, Bangkok

formation of democratic, cross-disability organizations which represent disabled people in rural and urban areas, and at all levels from grass-roots to national and regional level, and their full inclusion in decision-making processes.”

The development of disabled people's organizations (DPO's) in a number of Pacific Island countries has certainly been a positive step forward for those people with disabilities who have been able to become involved. People witnessing the development of DPO's are impressed by the involvement of new people with disabilities not known before by service providers.

Perhaps even more significantly, the involvement of people with disabilities in their own organizations represents a shift from a passive role of service-recipient to a much more pro-active role: “Previously they have relied on the service providers, but now we see them active and actually organise something by themselves. They are developing their own lives as well as their organisation”, observed one service provider. As these organizations are able to develop they will benefit even more people with disabilities in their country, as is evidenced in those countries where DPOs are further ahead in their development.

Limitations and barriers facing DPO's

While the role of such organizations might primarily be seen as self-help and self-advocacy, ‘advocacy’, however, is a construct not always easily and immediately understood even by some of those involved. It is understandable that, when asked, some of those involved in DPO's will say that what the organization needs to do is raise more money for people with disabilities, open a school or provide needed services as these are first order needs. Services, support and equipment are clearly desperately needed, but it sometimes takes some increased understanding of government, service delivery and public processes to recognize that a self advocacy organization can do a lot more if they do not necessarily have a hands-on role with direct support. As one PDO recognized, it is far better to have other NGOs and government focus on provision of service whilst a DPO plays “a watch-dog role.” Thus a DPO, even with limited resources can have a much wider impact, than if trying to provide the services itself.

The lack of understanding of DPO's is much greater from non-disabled people, including those operating in the disability sector. There is clearly confusion between the roles of government, non-government service providers and DPO's. Many do not realize the necessity of having a disability focal point in government to provide disability promotion, policy, programme and service delivery development and coordination with line Ministries, separate from the independent advocacy of a DPO. Though some do recognise the strategic importance of an independent DPO raising issues outside of government, while others work towards the same ends within government. Similarly, some (including some service providers) feel that the development of a DPO was merely a few people with disabilities drawing the meager resources from, and competing with, those organizations trying to provide services. This attitude by some service providers does not augur well for when the same DPO wishes to advocate for improved quality services.

Although these external barriers to understanding (and hence development) of DPO's are considerable their internal capacity remains the most significant barrier. In

general, many people with disabilities do not have the confidence and are not empowered sufficiently to self advocate, even as part of an organisation. As the Chair of one DPO said “We need to provide empowerment through esteem building for people with disabilities so we have many more people willing to speak up for themselves.” Further, their capacity to develop and agree on policy positions, strategic priorities and pursue them will tend to be severely limited in most cases while they remain unresourced.

Often there are not the skills, knowledge and time required to access and utilize existing government and non-government processes to change policies and service delivery. This is particularly challenging in communities where people with disabilities perceive that they “don’t even have the right to do that”. Where this capacity exists, it is often vested in one person or a best just a few, making the sustainability of such organization precarious.

In some respects the concept of ‘human rights’ can also be an unfamiliar concept to many Pacific Islanders with disabilities. Thus their ability to articulate that they may have the same rights as other citizens is not necessarily straight forward. Nevertheless, many countries do have some form of documented rights that people with disabilities could point to as the basis for their claims to equal treatment. However, to find and understand these rights can be difficult and does not always seem the most important priority for many people. This is possibly because ‘rights’ are a construct, conceptualized at a meta level above (and encapsulating) the range of needs usually identified by people with disabilities. There are often not many venues or spaces for ‘rights talk’ for people with disabilities, so it is little wonder that for many it is an unfamiliar concept.

The Regional Rights Resource Team (RRRT) has done some work with DPO’s and suggest that, as yet, people with disabilities

“...are unfortunately usually not skilled as advocates. People are treated as victims and people often act that way (as victims rather than as the holders of rights). A great need is to train up some leaders in each country, etc. From such leadership/advocacy training we will pick up other relevant tools, like the draft convention, change laws and advocate for a changed attitude to the rights of disabled people.”

“DPO’s are often seen as the enemy, not partners for improvement” was also a frustration commonly expressed by disability advocates to the Review. The non-confrontational culture of many Pacific Islanders is reflected in their approach to advocacy. They can even be perceived as aggressive merely for asserting themselves and speaking up to ensure they are not over-looked or just reliant on “pity”. Culturally appropriate forms of advocacy may need to be developed. However, in some cases this resistance may also be because the pursuit of equality threatens the long held positions of some community leaders. For example, as one service provider saw it, even for people with disabilities to form their own association “is disrespectful to the patron and people who have worked in this area for many many years...”.

In general, DPO’s tend to be impoverished organizations being supported (often exclusively) by an impoverished class of people. Even if the people with disabilities volunteering for the DPO are not always impoverished in terms of financial wealth, they often suffer from a poverty of time, simply due to the time and effort it might take them to complete other ordinary tasks. Most DPO’s have no resourcing for even

a desk, an office or a computer. Thus the focus on their own sustainability can divert them from their mission of advocating for people with disabilities.

The poverty of these volunteers and their organizations is not unrelated to the structural problems DPO's have, or are often perceived to have. That is, we often heard the view that governments, donors and service providing organizations assume that DPO's have weak governance, management problems and are therefore unsustainable. Although this may be true to the same extent as any other new and impoverished organization, the perception is exacerbated by incorrect assumptions about the capabilities of people with disabilities themselves. And when successful people with disabilities (such as those with jobs) became involved in DPO's, we even heard some discount their involvement, as if they were not *really* disabled.

The capacity of these organizations is further threatened by their subsequent inability to attract funding. They also have trouble attracting income because they are seen as competing with service provision rather than complementing it. Therefore, the very limited funding available for disability issues in Pacific Island countries often does not go beyond the most prominent service providers.

We also heard and observed the experience of a number of NGOs that "many donors are unwilling to fund an organization's core costs, but this is what's needed" The *Pacific Islands Forum Secretariat* also identified this dilemma. An administration base to enable people with disabilities to coalesce and have a base to advocate from appears to be a very powerful model. To ensure national coverage however "...often to actually reach out to people needs funding for the expensive internal travel costs for most countries". This may mean funding some or all of a DPO's strategic plan on an ongoing and 'patient' basis.

Although many organizations are frustrated at their inability to access funds, they also recognize that there is an appropriate time frame for self determined development for any DPO. Linked to the risk of funding projects for these organizations without covering core costs, is the risk of externally forcing their development too quickly. Few if any suffer from the risk of developing too quickly at this stage! However some may be unsustainable due to their inability to cover the core costs of administration, meetings, and ongoing member development, etc, before taking on specific projects.

Opportunities for DPO's

During the course of this Review, people with disabilities and others working in the field identified a wide range of possibilities and opportunities for DPO's. The challenge for many DPO's will be limiting this potential list to a few achievable strategic objectives, remaining focused on them, keeping their membership engaged (despite not taking up everyone's ideas) and of course resourcing and sustaining the work.

Given the considerable barrier created by attitudes towards people with disabilities identified above, awareness-raising has been an important objective for many DPO's. Depending on their size and capacity organizations have done this in different ways. Some have used the television, radio and print media to different degrees of success. Physical access issues are often good fodder for this work. For example, it was frequently reported in Fiji that the *Disabled Peoples Association* had gained national recognition for access issues in 'Disability Week' by conducting an Access Audit and

the *Cook Islands Disability Council* gained recognition of access issues for the future after protesting the inaccessibility of a new (donor funded and built) court house.

Unfortunately, often the media are more interested in stories accusing or embarrassing someone. Positive stories depicting empowered people with disabilities may be more difficult to promote through the media. Involvement in sport has proven to be an important way of showing the skills and achievements of people with disabilities, particularly in those many Pacific countries which highly value sport. There is still room however to involve people with disabilities in more mainstream sporting events (and achieve more coverage for those that are already involved). As one education official said, it is not enough to have "...the handicapped relay as part of the school sports day, these students need to be involved in other areas." He went on to say this is important because the public,

"...need to see people with disabilities treated as normal people. This should be done because people and families feel that if there are handicapped people in their families they are ashamed. But by promoting public awareness by including the handicapped this promotes public awareness and changes social attitudes."

The promotion of involvement of people with disabilities in public activities was therefore frequently seen as a key opportunity for DPO's. This was a view shared by a number of DPO's, government agencies, NGOs and people with disabilities themselves interviewed for this Review.

It was recognized that this form of 'public education and awareness raising' should go in concert with direct strategic advocacy. In most countries this would involve advocating government to develop disability policies and undertake legislative reform. In those countries where such policies exist, advocacy would centre around their appropriate implementation. Those who are aware of the Biwako Millennium Framework urged that this ought to be the basis of DPO's advocacy for policies and legislative change. Alternatively, if governments have greater affinity with the Millennium Development goals and targets, the two are quite consistent and one could easily be presented in terms of the other. The advantage of the Biwako Millennium Framework, of course, is not only that it is specifically focused on disability issues and targets, but it has also been adopted by the Heads of Pacific Island governments.

DPO's could profitably advocate for effective implementation of the recommendations of the *Biwako Millennium Framework*, especially as the period for mid-term reporting approaches in 2008. Aspects which they would concentrate on could differ between countries, as would the method of implementation. There could be common approaches however and this may therefore lend some of this work to regional cooperation and support (see Section 5.1).

Some who are further down the policy and legislation path have found that appropriate, quality implementation requires that people with disabilities are involved in the policy development and implementation process. This has been shown to provide tangible benefits in terms of the quality of policies and programmes and their sustainability in the field. This however requires the development of a certain skill and knowledge level not always immediately available in volunteer-based organizations with few resources.

The frustration for some was exhibited by the serious suggestions of becoming much more politicized to the point of supporting people with disabilities to run for parliament, as was suggested in at least one of the focus groups. Again, the desire to become more politicized was not always matched with the necessary understanding of political processes and how best to influence them. Some did recognize that the DPO development process might be well served by closely linking with existing broadly based advocacy organizations for support and mentoring, to have the disability cause presented as a suite of other social equity or human rights policies, and to show solidarity with other causes (“advancing the position of people with disabilities is not a competition with other disadvantaged sectors of society”).

The data collection work initiated by *Inclusion International* is in demand by a range of stakeholders (communities, DPO’s, service providers, government and international agencies). Although there are opportunities to re-target this work depending on the objective and target audience (as discussed in Section 3.3), with appropriate resources and regional support DPO’s are well placed to lead and/or further promote this work and its findings.

In many countries data collection has not been completed. And in some there are opportunities to begin data collection exercises, having learned from the work already done in other Pacific Island countries. Either way a well resourced and strategically planned data collection process should be a well-received part of any DPO’s work plan (see Section 3.3).

Examples of the wide range of other suggested areas for DPO work identified during the consultations include:

- training people with disabilities to speak up, with an ability to promote self advocacy and human rights (in particular young people);
- facilitating community education and community meetings;
- bringing in speakers with disabilities for other special community events (such as International Women’s Day);
- lobbying for a social welfare budget with other disadvantaged groups;
- advocating for a government department or focal point on disability;
- getting organizations to provide equipment such as walking sticks, wheelchairs, medications, etc as there is no money for this in the home or the hospital;
- lobbying for improved access to education including scholarships for people with disabilities;
- lobby for access to education, especially on outer islands;
- uniting people with disabilities, developing a strong voice to fight for rights;
- promoting awareness of disability issues in churches, schools, etc;
- involving families in identifying needs and how those needs might be met;
- assisting people with disabilities into mainstream employment; and
- conducting and promoting outreach to remote people with disabilities.

A long term challenge for most DPO’s will be to ensure their broad representation. In general most of the leadership of existing DPO’s is by people who are blind/vision impaired or people with physical disabilities. This often occurs as organizations like

this develop, but considerable effort must be put in to ensure other disabilities are appropriately represented. In particular, often people with mental illness and intellectual disabilities find it harder to become involved.

The effects of disability are obviously quite different for different disability groups, but it is also important to consider other differences among the wide range of people with disabilities. For example, DPO's would ideally continue to work to ensure that they achieve and maintain at least a gender and age balance in their leadership and membership. Where there are different ethnic and religious groups in a society, these also need to be considered and included.

4.3 POLICY AND LEGISLATION

There is currently no legislation which specifically promotes the human rights of all people with disabilities in any Pacific Island country. There are some disability policies designed to reduce the inequalities experienced by people with disabilities and some legislation which refers to some disability groups. Some legislation provides some indirect rights, for example, the right for all children under 15 years to an education. The lack of disability-targeted legislation, however, is seen as a barrier to many people with disabilities asserting their rights. Fiji's Constitution stands out as one providing that no-one shall be discriminated against, on the basis of disability. However, there is clearly an implementation gap between the Fijian Constitution and experiences of people with disabilities. .

As McKinstry found in the *Inclusion International* review of disability related policy and legislation (see Section 3.2):

“Persons with a disability are known to be marginalised in Pacific countries, and legislative frameworks, mostly inherited from pre-independence days, do not cater for their rights nor guarantee services.”

Many regard legislation and policy development as the key step to national implementation of the *Biwako Millennium Framework*. Further, it is widely believed among those interviewed for this Review that legislation and policy can act to stop discrimination. However, it should be said that in general, the importance accorded to legislation and policy was higher in the minds of representatives of regional organizations, than among NGOs, DPO's and people with disabilities.

The majority of regional and international organizations (particularly those with a policy focus) are intent on the need for policy and legislation to make the necessary changes for people with disabilities in the region. While some agencies are interested in disability policies and legislation generally, others target specific areas. For example, as would be expected, the *United Nations International Labour Office (ILO)* is interested in countries introducing inclusive employment and training legislation.²⁷ One regional agency advised that after the policy and legislation review “the gap is now clear in policy and legislation – we can give DPO's the findings to take forward”. Most regional agencies are aware, however, that assistance must be provided to governments to develop policy which is appropriate for their country. It was suggested by at least one of the agencies that this may be the best use of regional

²⁷ ILO C159 *Vocational Rehabilitation and Employment (Disabled Persons) Convention, 1983, promotes open employment/training for people with disabilities via positive measures.*

disability focused funding. Some also see the development of an *International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, together with the existence of the *Biwako Millennium Framework*, as a basis on which to call on Pacific governments to introduce necessary legislation and policy.

An important use for policy and legislation was succinctly put by one international agency: “legislation and policy would give [pin-country] advocates a club to hit governments with”. It was also recognized by some agencies working in the field, however, that the introduction of policy and/or legislation would not fill the advocacy capacity gap (discussed in Section 4.2): “We need to build DPO institutional capacity. They are not able to go out and demand the sort of compliance that is required with their current resources and capacity.” The few international agencies working on disabilities issues expressed willingness to support DPO’s in understanding and/or advocating for particular legislative change. A few examples of this collaboration already exists, for example ESCAP’s current work in PNG (and other earlier in-country work), RRRT’s work with *Fiji Disabled Persons Association* and *Vanuatu Disability Promotion and Advocacy Association*.

Governments are also supporters of legislation and policy development. The concern, however, is if this comes to be seen as an end in and of itself. As the slow growth of a focus on disability in the Pacific is relatively new, there are few examples of where legislation or government policy has really made a difference. The evidence suggests that where it has made a difference it has mainly been due to the motivation and tenacity of key individuals, both inside and outside government. This was also a view we heard in the consultations, including from some government officials.

Many NGOs and people with disabilities, however, remain skeptical of the benefits of legislation as they see the implementation and action gap which often exists regardless of legislation. For example, the existing minimal legislation which people with disabilities could potentially benefit from is frequently not implemented. A range of reasons are cited for this, but the most common one is the lack of resources. Often, however, disability funding issues are forced down the priority list behind other expenditure areas due to the perceived unimportance of the issue. Strategies implemented by those organizations operating on a sub-sectoral basis (for example, in employment, education, and health, etc) show greater promise when they take a multi-pronged approach:

- 1) a focus on legislation and policy development;
- 2) empowering people with disabilities to enable them to take up their rights (for example, through training, equipment provision, and support); and
- 3) actively creating sustained participation and community involvement in different sectors of mainstream society (for example, through employment, socializing, etc).

At the time of writing this report, Fiji was passing legislation to require employers of a certain size to ensure that at least two percent of their employees are people with disabilities. Although laudable, many are aware of the implementation issues this will present given the low number of trained people with disabilities, enforcement difficulties and attitudinal barriers to including people with disabilities in the workplace. Also in Fiji it is arguable that one of the success factors for the new accessibility building code is the existence of a local DPO (*Fiji Disabled Peoples*

Association) which has been willing and able to conduct high profile public access audits.

Some even suggest that without the right people and resources, disability policies and legislation are not very useful. According to the *Cook Islands National Disability Council*, the disability policy was prepared in 2002, but very little was done about it until coordinating and implementing positions were funded in late 2005.

In general, it is clear that without those willing to implement, government and non-government services able to provide support, and advocates willing and able to continually promote the needs and quality issues, legislation and policy may not be as effective as some hope.

Often a pre-requisite for policy development and government programmes is the existence of a government focal point. The lack of a focal point in government for many countries is therefore a significant stumbling block to the development of sound policy in the area. Countries which have a government disability focal point have found that it "...has been crucial to making change of policy and legislation from within". Without someone within government to advocate on disability issues, many mainstream policies and programmes continue to exclude, or at least ignore, people with disabilities. The more active and more highly respected a disability focal point can be within government, the more disability issues seem to be integrated in mainstream policy and specific policy is promoted where necessary. Ideally the focal point is located in a central ministry such as the Office of the Prime Minister or the Ministry for Internal Affairs (or equivalent) so that all areas of government can be targeted. (Having said this, *Fiji's National Council for Disabled Persons* has apparently had considerable success while located in the Ministry for Women, Social Welfare and Poverty Alleviation. Though this may be related to the involvement of some key individuals.)

The role for the government focal point does not stop with the development of an overall disability policy. It must provide coordination and an overview of specific (line ministry) policy development and implementation. The approach taken by the *New Zealand Disability Strategy* is a useful model and has been mirrored to some extent by some Pacific Island countries, such as the Cook Islands. The combination of a policy position and a limited term strategy has the benefit of simultaneously articulating government support for disability, setting achievable targets for change and involving all ministries as appropriate (preferably with specific reporting requirements. The Cook Islands policy summarises the approach:

"The coordination of services minimises the likelihood of duplication and is more likely to ensure that services and programmes are more effectively delivered and strategic alliances between agencies are more likely to be developed and synergies achieved. This requires the sharing of information and the establishment of communication channels between government ministries and divisions as well as the establishment of alliances and working partnerships with island administrations and councils and non-governmental organisations."

Because much international activity occurs on an inter-governmental basis, the lack of a disability focal point within government has also meant that governments generally do not raise the issue at an international level and are unable to take full advantage of regional activity occurring around disability. The initiative of the Vanuatu Prime

Minister in promoting disability at the *Pacific Islands Forum Leaders* meeting in Wellington in 2003 provides a notable exception. The very few international agencies working on disability identify the lack of a focal point as “the big gap” for many countries. As they expressed to the Review, this usually means that “the people in government working on disability just do not exist”.

The international agencies which have not taken their own initiative in the area of empowering and supporting people with disabilities appear to be waiting to respond to Pacific Island country priorities. As one UN agency observed, “There is no reason why it could not be put on our agenda if the local country-government support was there.”

Even those donors that provide funds to country based NGO’s tend to provide NGO’s with only a small proportion of their funds. The vast majority of funds are provided on a government-to-government basis. In general, the development approach of responding to Pacific government priorities is a sound one. This does not necessarily prohibit donors from asking Pacific governments when they are framing their priorities how they will engage people with disabilities in development, in a similar way to how the spot light has been put on women in development. This need not undermine sector-wide approaches. The continued ignorance of disability issues, however, will continue to exacerbate the current ‘catch 22’ of disability visibility (identified in Section 3.6 above), and compound the gap between disabled and non-disabled Pacific Islanders. In particular the lack of governmental focal points are a key continuing barrier, while policies and legislation will only make a significant difference if they are appropriately implemented and resourced.

4.4 DISABILITY SERVICES

Although advocacy has been identified above (in Section 4.1) as necessary to empower Pacific Islanders with disabilities and reduce the inequalities they experience, it is of course not a sufficient condition. Many of the rights and entitlements argued for will either require services and support for their effective enjoyment or specific services may be the end being advocated for. Sometimes these services are costly, but not always. The greater problem, however, seems to be the low priority afforded to the rights of people with disabilities.

Most people with disabilities in the Pacific do not receive any formal services or support. Informal services and support from family and neighbours carries the risk of vulnerability and inconsistency. It also risks people with disabilities being viewed as objects of charity, with support only given to the extent that someone else feels it is the limits of the disabled person’s capacity. Notwithstanding the fact that villages and families will always play an important role in assisting people with disabilities, formal services can usefully augment this informal support, and strengthen and support that informal support – rather than leaving it vulnerable to whatever pressures it may face from time to time. Well-constructed outside services also offer the possibility of raising someone’s potential beyond that already assumed for them by others.

Those services which do exist are increasingly becoming stretched. Often services originally designed for people with low level disabilities are having to focus their efforts on people with much higher needs. One service reported that they previously closed on weekends, but because of their changing client profile they have become a 24 hour 7 day operation. Some services seem to try to extend their support to waiting

list clients through home visits, but this has had varying success due to resourcing requirements and organizations' differing abilities to monitor quality and appropriate service outreach. In some countries visiting public health nurses seem to see some people with disabilities not otherwise receiving services - hence the value in using such sources in data collection and identification strategies (see Section 3.3).

As it is frequently assumed that *any* services provided to people with disabilities are good, there has, to date, been little room to discuss issues of appropriateness or quality of services in many Pacific countries. Therefore the Review was readily able to identify situations in a number of countries where, for example, people with mental illness had prison as their only accommodation option if unable to be cared for by family; people who are blind, physically disabled or mildly intellectually disabled were institutionalized in segregated facilities with limited outside contact; people were provided with repetitive, poor quality training with little prospect of exit to employment; and vocationally training was provided for others in areas they do not wish to work. In all cases we observed, these situations not only existed but were generally accepted without question or apology. Some service providers are accused by advocates and other service providers of "stagnating services for people with disabilities". There was also, what is perhaps the even more insidious accusation of not pushing or challenging people with disabilities enough, in the ways that non-disabled people are routinely challenged. Many felt that this would continue while the services remained closed, separate and segregated.

From an outsiders' perspective, the language used by some service providers seems to indicate a proprietary interest in *their* service and the people with disabilities that use it. This is in marked contrast to many mainstream services which have at least some recognition of community ownership and participatory development. As a result people with disabilities would not have a say over the quality or type of services provided to them by such organizations.

It is not unusual that parents and the broader community tend to think of specialized services/institutions first before inclusive or mainstream approaches. It is natural that parents feel that their child will be at less risk and have his/her needs better met in a specialized setting – especially if this is the only option they think might be available, or if 'mainstreaming' means ignoring rather than including. There appears to be a major shortfall in the number of organisations willing and able to bridge the gap between specialized and inclusive approaches to ensure that mainstream services are accessed to the limit of a person's capabilities, rather than the limit of the services capacity.

Mainstream Services

Segregation and separation fits well with, and indeed helps to reinforce, high levels of shame about disability in a society. It also fits well with a 'charity', rather than a developmental approach. This is not to argue that there can be a place for specialist services and programmes. However, there seems to be minimal inclusive education, training or employment in the Pacific. There are examples of attempts at inclusive education, but without a wholesale shift of approach, special (segregated) education continues to be the rule. For example, in Fiji some deaf students went into a mainstream school, with the help of a sign interpreter. When the head of the under-resourced school discovered that the sign interpreter was also able to teach science, she was quickly shifted into science teaching duties.

It is possible, nevertheless, to gradually change this approach. In Tonga after considerable advocacy from a range of NGO's (including the newly formed DPO), pressure from an officer responsible for Special Education Officer, findings from the pilot data collection process and a significant increase in funding for Education, the Director of Education agreed to establish a disability inclusion unit within the ministry. The Unit will promote inclusive education, support related teacher training and facilitate provision of equipment. This commitment was made in July 2005 as a result of a number of congruent factors: support from the Director of Education, new funding, and pressure from within and outside of government. It will be important for this to be closely monitored, as it was reported that past commitments in some countries were not carried through, or at least not in a timely manner.

PART 5: Where To From Here?

New Zealand Agency for International Development (NZAID) currently seeks “...a clear, strategic direction for assistance in the area of disabilities for the next five years” for NZAID’s Pacific Regional Health Programme, within funds not exceeding NZ\$300,000 per annum. As well as recommending an approach for NZAID, this Review has also been commissioned to review the *Inclusion International* Pacific Regional Disability Project, provide a summary of current key regional issues and activities in the area of disabilities, and evaluate the capacity and capability of key indigenous regional agencies, in particular the Pacific Disabilities Forum.²⁸

The policy context provided by the complementary and congruent perspectives of NZAID’s Health Policy and Human Rights Policy, the New Zealand *Disability Strategy*, the *Biwako Millennium Framework* (BMF) and the Draft *Convention for the Rights and Dignity of People With Disabilities* (see Section 2.1) provides the perfect platform to support Pacific Islanders with disabilities in a more progressive way than ever before. Moreover the consultations undertaken for this review and the analysis (provided in Parts 2, 3 and 4) lead us to see definite key strategic priorities for action at this time in the Pacific for people with disabilities:

- basic awareness raising and advocacy cannot be stressed enough as a high order need which will create the receptive environment required for other change;
- activities supported by the NZAID Pacific Regional Disability Programme and its philosophy must gain leverage over other resources as well, if the ambitious objectives of poverty reduction and social inclusion are to be realised in any meaningful way;
- strong disabled person’s organisations (DPOs) at a national level need to be supported to take up regionally and locally identified needs with appropriate local application; and
- support and resources will also be required at a regional level to enable this necessary in-country work to occur.

This occurs within a framework where the key strategic objective is the elimination of poverty amongst people with disabilities in the Pacific. It is recognized that this is more likely to occur if the participation and inclusion of people with disabilities at all levels of society is fostered, by both empowering Pacific Islanders with disabilities and reducing the inequalities they experience.

5.1 WHAT IS NEEDED AT A REGIONAL LEVEL

This section considers the potential contribution of regional level activity to the position of people with disabilities in the Pacific, through: regional advocacy and development; sharing of good practice; and technical assistance.

²⁸ NZAID (2005) “Terms of Reference: Review of Pacific Regional Disabilities” – see Appendix VIII

Regional Advocacy and Policy Development

Despite the considerable work which has been undertaken by some committed people (see Sections 2.3 & 2.4), regional level work on disability issues in the Pacific has been limited and remains fragile. Indeed, despite the recognition, by many of those consulted in this Review, of the importance of strategic regional action (such as systemic advocacy, policy development, funding, resource development and coordination), there is also a strong belief that the most crucial action to promote the position of people with disabilities needs to occur at the country level. We do not dispute this view. It will be important not just to be led by the availability of funding for regional activities, but to find the right balance so that regional activity is complementary to, and ultimately enhances country-based action. The crucial question, then, is what is the most effective focus for any regional activity, if any, in order to achieve this.

Some have observed the lesson from other sectors is that it is often useful to bring together policy people and relevant Ministers *outside* of their country (for example at a regional or international forum) to seek agreements and undertakings. This is particularly important for disability issues which are often pushed down under other priorities within country. As one NGO leader commented:

“It usually takes a leader to be presented with these issues outside of country to under stand that something is really a problem. For example, it was only when the deputy PM recently went to the Women’s Conference in New York that he agreed to sign CEDAW [the Convention on the Elimination of All Forms of Discrimination against Women, adopted by the UN General Assembly in 1979].”

The success of the Pacific HIV-AIDS Strategy was also cited as an example of good regional strategic advocacy. However, it is important to note that for a number of reasons at a global level, disability issues do not seem to attract either the policy focus or the level of funding of HIV-AIDS issues. As a result, disability advocates must generally work harder with fewer resources, and disability infrastructure and organizations are much less developed.

In the disability field, the agreement by all Pacific countries to sign up to the *Biwako Millennium Framework* (BMF) is a good example of where strategic regional activity needs to be followed up with country-based information, development, advocacy and resources. Ideally the commitment to the BMF would be followed by donors committing to a regional resource to assist governments to develop disability policies and strategies - such as the work currently being undertaken by the Pacific Operations Centre of the United Nations Economic and Social Commission for Asia and the Pacific (ESCAP). This could bring together the goals of the *Biwako Millennium Framework* and local findings, such as those identified by *Inclusion International’s* disability identification surveys. The demand for ESCAP’s services in this area are considerably outstripping their capacity and needs further resourcing - lest commitments under the *Biwako Millennium Framework* become a distant and unfortunate memory of unfulfilled commitments for many countries. It is our view that the political opportunity currently afforded to people with disabilities in the Pacific by the *Biwako Millennium Framework* is far too important not to ensure that its impact is maximized.

The adoption of the *Biwako Millennium Framework* by all Pacific leaders is clear evidence that regional advocacy can be effective. Given the need to build on this momentum, future opportunities for collective advocacy across Pacific Island countries will also need to be identified and utilised. Collaboration across a range of agencies, organizations and countries has been a hallmark of the success so far, and will need to continue to make the best use of any regional resources for disability issues. Although Pacific-wide advocacy is attractive due to the economies of scale involved²⁹, organizations undertaking such advocacy will need to allow for the diversity of cultures, needs and development of different Pacific Island countries.

A key part of any regionally based advocacy will be partnering with country-based disabled persons' organisations to ensure that agreements made at a regional level are effectively followed up locally. Depending on the issue and the strategies developed this will probably involve, as well as the provision of information, someone traveling to individual Pacific countries to work with disabled persons' organisations before, during and after regional advocacy work. The national disabled persons' organisations could then be supported to advocate to government, ministers, service providers and the public as necessary. This will maximize the potential for a consistent regional approach, provide the focus of human and financial resources at a regional level on a particular theme, whilst enabling differing national needs to be responded to within that theme. Someone currently working at a regional level advised, in reference to regional and local policy development, of the importance of the "...need to strengthen disabled persons' organisations, as they just don't yet have the capacity to do this advocacy." Some available research³⁰ suggests that building effective advocacy capacity for an organization could be expected to involve areas such as:

- creating a strategic communications plan;
- making member and constituent education a priority;
- collaborating with other organizations; and
- interacting directly with policy makers.

The same research also suggests, for example, that general unfocussed public education and awareness-raising is less effective than specific advocacy campaigns targeted at achieving particular policy or legislative goals.

Some Pacific Islanders with disabilities also suggested that effective follow-up is necessary for accountability and transparency purposes. They were concerned that unfortunately, because of its low priority, funding and other resources meant for disability-related work may end up allocated elsewhere or not eventuate at all.

A number of people also identified the potential for more regional-level donor activity. Many advocates and service providers were concerned at the time and energy wasted on unsuccessful funding applications. One NGO said "Many of even the

²⁹ This 'economy of scale' refers perhaps even more to the availability of time and energy of skilled and informed individuals, as it does to any efficiencies from pooling financial resources.

³⁰ See for example Susan Rees (1998) *Effective Nonprofit Advocacy*, Nonprofit Sector Research Working Paper Series, The Aspen Institute, Washington
http://www.nonprofitresearch.org/newsletter1525/newsletter_show.htm?doc_id=16334

private donors would rather give larger amounts for the whole region.” Sometimes onerous reporting requirements are better aggregated at a regional level, rather than done inconsistently by volunteers (not always suited to administrative work) at a country level.

Given the different stages which different countries are at with respect to development for people with disabilities and related advocacy and service capacity, there are also opportunities for organizations from different Pacific Island countries to provide peer support across the region. An excellent example of this was the support provided by Nuanua o le Alofa (NOLA), the Samoan disabled persons’ organisation, to their Tongan counterpart, Naunau O e’ Alamite Tonga Association (NATA) for their initial development and for the disability identification surveys undertaken with Red Cross in Tonga. There are a number of skilled advocates in the region who could be resourced to provide the type of advocacy support discussed above. This would strengthen the linkages between countries and reduce the isolation felt by many disability advocates. (The general issue of sharing good practice is discussed further below.)

In global networks and agencies, the Pacific is usually incorporated within a broader Asia Pacific region. Pacific Island countries, despite their differences clearly have a lot more in common with each other than with most Asian nations, and are often swamped by the weight of the significantly greater population base, organizations, services and research in the Asian part of Asia-Pacific. For Pacific voices to be heard, advocacy work will generally require a specific Pacific focus. When discussing the range of Asia-Pacific work and organizations, several people working at a Pacific regional level identified the importance of the “need to put the *Pacific* into *Asia-Pacific*”.

Sharing Good Practice

Sharing of good practice is another opportunity with improved unilateral and multilateral networks across the Pacific. Most government and non-government bodies interviewed who had some success in improving the position of people with disabilities, expressed a desire to share what they had done and lessons they had learned with counter-part organizations in other Pacific Island countries. We have no reason to believe there would be any less good will in sharing lessons learnt from other countries as well, and the limited feedback received in other Pacific Island countries reinforces this belief. Some of these successes include development of legislation requiring larger employers to employ people with disabilities, a government focal point for disability, and improvements in physical access and planning requirements. It was also suggested that there are examples of relevant successes from New Zealand and Australia which could be passed on, such as the recently developed “tool kit” for the implementation of the *New Zealand Disability Strategy*. The good will and interest in mutual support should not be under-estimated, and was often spontaneously offered to the Review team. However, these rich resources are seriously under-utilised at present. An easy and accessible mechanism, or perhaps a number of mechanisms, are needed to facilitate this potential flow of information, ideas, encouragement and support.

Ideally information sharing would occur with the issues faced by governments, service providers, advocacy groups and donors in mind. This would enable current and potential donors to engage with the issues and make contacts with others

operating in the region and in-country. Although other forms of communication would be complementary, face to face communication seems to work best. Electronic communications is rapidly increasing, but seems to remain the least preferred method. This may be partly due to the fact that many Pacific Islander cultures are considered to be ‘high context’ cultures and have a strong oral tradition³¹. Regional resources to support and empower people with disabilities are likely to remain scarce. Therefore funding regional workshops (which are relatively expensive in the Pacific) will be viewed with suspicion by some donors. However, it is difficult to envisage how effective regional networks and support could be developed without building in some regular (albeit infrequent) face to face interaction and sharing, to supplement and encourage other forms of communication. The high value of such face to face communication, and the considerable benefits identified through this Review (see for example Section 3.4 and appendix VII) offer strong arguments for investing in such approaches in the Pacific – even if they need to be supported by other, more regular (albeit less effective) communication channels, such as email, in between.

Technical Assistance

There is considerable demand for technical assistance in the region in a range of areas. Some of those identified in the course of this Review as being of highest priority to improve the position of people with disabilities in the Pacific, include advocacy skills, service provision good practice, organizational capacity building, disability legislation & policy development, disability teacher training, and early disability identification & intervention.

As discussed above, advocacy at public, government and service provider levels would be a necessary key component of any strategic regional approach. As we have also noted, for some, advocacy is still a new concept³². It is also an area in which, there are specific skills and information which can be acquired and which the research suggests are more likely to lead to more effective advocacy.

Similarly technical assistance is acutely needed on good-practice service provision (see discussion in Section 4.4). Such technical assistance would best be provided by Pacific Islanders with disabilities. Where that capacity does not exist, it would be useful (and more sustainable) for other support to be brought in to assist in a way that also helps transfer such important skills and knowledge to people with disabilities in the Region. This is consistent with NZAID’s approach to expatriate involvement in other programme areas – for example, New Zealand NGOs funded under Voluntary Agency Support Scheme (VASS) are required to demonstrate “...the process by which the particular expatriate skills will be transferred to enable the role, if ongoing,

³¹ *High context* cultures are those that are more likely to emphasise relationships, trust, consensus and indirect communication, while *low context* cultures are more likely to emphasis logic, facts, directness and individual interests (Edward Hall (1959) *The Silent Language*, Prentice Hall , New York.)

³² This is not necessarily restricted to Pacific Islanders with disabilities. For example, *Research Information for Independent Living* www.getriil.com/advocacy.html identifies research indicating that less than one third of Americans with disabilities have effective advocacy skills, but it also concludes that there are specific and teachable advocacy skills in the areas of self-advocacy, individual advocacy, systems advocacy and legal advocacy.

to be met locally in the future, [and] the timeframe during which expatriate involvement will be phased out”.³³

Organizational capacity building for disabled persons’ organisations and service provider organizations would also ideally be provided by Pacific Islanders with disabilities. The Pacific Islands Association of NGOs (PIANGO) has identified a number of key principles for effective capacity building, which are relevant here. It should be

- participant owned and directed;
- focused and flexible;
- process oriented;
- value-driven
- context specific;
- interdependent; and
- multifaceted.

Skills in management, governance, membership development and fund raising have been identified by participants in this Review as potential specific areas of assistance. The issue was best captured by a regional agency, who argued: “We need to build the institutional capacity of disabled persons’ organisations. They are not able to go out and demand the sort of compliance of governments that is required with their current resources and capacity.” However it is also important not to fall into the trap of negative stereotypes about disabled persons’ organizations (see Section 4.2). They also have considerable capacities, skills and knowledge which can be built upon and shared. And it can be counterproductive to offer repeated one-off training workshops, when they lack the continuity of even basic level resourcing.

Nor is capacity building just another way of describing ‘training’ and ‘funding’. Kaplan³⁴ argues these are, in fact, the least important aspects of NGO capacity and proposes a much broader conception which includes, in order of importance:

1. “a *conceptual framework*, which reflects the organisation’s understanding of the world;
2. “an *organisational ‘attitude’* which incorporates the confidence to act in and on the world in a way that the organization believes can be effective and have an impact...;
3. “clear organizational *vision and strategy*, and sense of purpose and will, which flows out of [this] understanding...;
4. “defined and differentiated *structures and procedures* which reflect and support the vision and strategy;
5. “[and only then] relevant individual *skills, abilities and competencies*; and
6. “sufficient and appropriate *material resources*.”

³³ Guideline 6: “Involvement of Expatriates” in Voluntary Agencies Support Scheme Handbook (2004) <http://nzaid.govt.nz/vass/docs/vass-handbook-part-f.pdf>

³⁴ Allan Kaplan (1999) *The Development of Capacity*, (Development Dossier NGLS127) United Nations Non-Governmental Liaison Service, Geneva

Technical assistance on disability policy and legislation is in high demand in the Pacific (as discussed in Section 4.3). This work, currently being undertaken by UN ESCAP Pacific Operations Centre lends itself to expansion, potentially in its next stage with Pacific Islanders with disabilities themselves delivering technical assistance. This would not only take advantage of the useful resource offered by many people with disabilities in the Pacific, but also work to reinforce and strengthen those skills, as well as provide potentially very powerful role models. The development or adaptation of public policy tools and templates has also been suggested as a potential method of assistance here - for example, the development of draft model legislation. However, as we have noted earlier when reviewing the impact of the regional review of disability policy and legislation, without adequate in-country capacity for follow up, a focus on developing model legislation alone is unlikely to have significant impact.

Given the fundamental need for equitable access to education for people with disabilities, teacher training in this area registers highly as a specific area of targeted need. Such training should recognize the need for both mainstream and specialized education (where necessary). In some countries so few teachers have expertise in special education that those who do have those skills are drawn into that field on a full-time basis. This reduces skilled teachers for inclusive education in mainstream education and deters some teachers from gaining the qualification. It was suggested by an education official that the Pacific Regional Initiative for the Delivery of Basic Education (PRIDE) would be well placed to support increased disability training for teachers, as what is needed is country-based training not just regional level training. Others suggested a regional project with a team of specialized trainers to assess and deliver relevant intensive training in each country. One special education teacher encapsulated the issues by saying, “The inclusive education idea is challenging, as teachers don’t know how to support students in this situation. Training is very much needed.” It is beyond the scope of this Review to recommend the best method for delivery, but what is clear is the great need for significant investment in disability teacher training in the Pacific.

The other priority need especially identified in this Review, which would provide improved access to educational opportunities and longer term benefits for people with disabilities in the Pacific is early identification and intervention (see Section 4.5). Although UNICEF, for example, agreed that they would be well placed to do this work, it could similarly be undertaken on the same basis as the *Inclusion International* disability identification surveys, but with the assurance of follow-up service-provision built in. Some criticism was leveled at projects that identify disabilities without a plan and resources already in place to provide needed assistance. Any future identification work needs to be mindful of this issue (see Sections 3.3 and 3.7).

It was also recognized in discussions that there are important community and family roles to play in early identification and intervention, as people can help by being more aware of appropriate norms of child development. Community workers related that,

“Often we just lump all people with disabilities together, as we don’t know much about disability. Often we see kids who suffer some kind of disability early on and they are further disadvantaged as we don’t pick it up. If we tested early to know what assistance to give, most of these kids could stay in the normal class room.”

The general risk in providing technical assistance is that it can be rolled out from a central provider when the intellectual capacity, skills and commitment exist, but the resources that are lacking. This may be because it is often easier to monitor professionally delivered and centrally managed technical assistance than funding for direct service-provision, but skills and knowledge alone are insufficient to reduce the inequities faced by people with disabilities and a more developmental approach is required to be an essential part of the strategic mix.

5.2 POTENTIAL INDIGENOUS REGIONAL DISABILITY ORGANISATIONS

One of the specific objectives (number 3) of this Review is to identify and evaluate the capacity and capability of key indigenous regional organizations. In considering the best way forward for the support of disability work in the Pacific region a number of assessment criteria were used. These criteria go to the quality and nature of existing and potential regional organizations in the Pacific. The aim is to identify the organization or organizations best able to take up the next stage of the work now required to take forward the position of people with disabilities in the Pacific. This will involve a capacity to: build on the useful groundwork provided by the four elements of the Inclusion International project reviewed in Part 3; effectively respond to the critical issues identified in Part 4; and take up the opportunities identified in Section 5.1 above.

No single organization is likely to be able to undertake all of this work itself. Nor is any single organization likely to have all the capabilities required without limitations. What is clearly needed is an organization which, on balance, has an appropriate mix of strengths, and is able to lead activity in some key areas, partnering with relevant experts in some areas and acting as a catalyst for yet other activity.

On this basis, we have identified the following criteria as useful for identifying and assessing the relative strengths and limitations of appropriate regional organizations. The organization will need to be:

1. focused on people with disabilities, their empowerment and equitable treatment;
2. substantially governed and advised directly by people with disabilities;
3. broadly representative of the people and issues in the disability field in Pacific Island countries;
4. capable of efficiently delivering regional outcomes (especially in the areas of advocacy, communication, and participation and development); and
5. respected by other organizations and agencies in the region (especially those with the resources and or power to effect needed changes for people with disabilities).

There are a number of organizations which could be considered as a potential organization to take the lead in the next stage of development in improving the position of people with disabilities in the Pacific. These include:

- Pacific Disability Forum (PDF);
- Disabled People International, Oceania (DPI Oceania);
- Inclusion International, Asia Pacific;
- Asia Pacific Disability Forum (APDF);

- Rehabilitation International, Asia Pacific;
- one of the regional or international inter-governmental organizations operating in the Pacific; or
- a new organization created and developed especially for this purpose.

None of these organizations met all criteria without at least some reservations. There are also a number of other organizations working on social justice issues more broadly in the Pacific (including disability issues in some cases). These would have comfortably met criteria 3, 4 and 5. Criteria 1 and 2 however were considered sufficiently central to eliminate these organizations from further detailed consideration.

Two organizations operating at a supra-regional level (Rehabilitation International and APDF) were considered unable to sufficiently meet criteria 3 and 4.³⁵ Further there is some risk that they may not meet criteria 5 in all respects – though this was not fully explored.

DPI (Oceania) could meet all except criteria 3. As discussed in section 2.3, DPI Oceania neither claims nor aspires to be able to represent or be supported by all country-based stakeholders. It has a much more specific brief to represent and support its national member organisations (with their specific membership criteria). Indeed this was part of the reason for the development of the Pacific Disability Forum in the first place, to enable a wider participation - which is considered in more detail in Section 5.3.

Regional and international agencies based in the Pacific comfortably meet criteria 4 and 5. In general however they tend to be too rigid in the structure to substantially meet criteria 1,2 and 3. Moreover, their need to act congruently with the wide range of other responsibilities inherent in regional politics and development mean that they could not always publicly advocate completely and strongly for people with disabilities – which is the sort of approach people are seeking.

As currently the lead agency funded under NZAID’s Pacific Regional Disability Programme, we will consider the strengths and limitations of Inclusion International (Asia Pacific) in a little more detail. As discussed extensively in Part 3 the work of *Inclusion International* in the Pacific has been extremely positive. Many of *Inclusion International*’s activities have had ongoing positive development impacts and seeded other important work. Moreover, *Inclusion International*, through the NZAID Pacific Regional Disability Programme and previous involvements has a good profile among disability organisations and governments in the Pacific.

However, criteria 2 and 3 are not met by the current structure as a supra-regional committee of a global NGO. Direct Pacific involvement, and especially involvement of Pacific Islanders with disabilities, in *Inclusion International* leadership is severely limited. NZAID has clearly expressed a specific interest in supporting an “indigenous Pacific disability organization.” This is also consistent with the assessment of bodies such as UN ESCAP that “the targets of the Biwako Millennium Framework demand support for the formation of democratic, cross-disability organizations which

³⁵ *Rehabilitation International* and APDF were not able to be interviewed directly for this Review. Assessment was made from publicly available information.

represent disabled people³⁶”, clearly also implying by their analysis that such organizations would need to represent and be controlled by Pacific Islanders with disabilities. In summary,:

- *Inclusion International’s* work in the Pacific is not governed and advised directly by Pacific Islanders with disabilities;
- *Inclusion International* as an organization is not representative of the people and issues in the disability field in Pacific Island countries;
- It is timely to build on *Inclusion International’s* work and promote a regional approach to disability that is Pacific owned;
- Continued local, country-based work alone will not create the leadership and attitudinal change required at all levels to make a difference for Pacific Islanders with disabilities; and
- Pacific Islanders (supported by others) are better placed to lead and advocate regionally and internationally for resources and rights.

It might also be possible that a new organization could be created, with invited membership from many of the organizations considered above. Such development may not, however, be sustainable. The flexibility which such a new organization might offer already exists in the Pacific Disability Forum (PDF), which was, in effect already created to be such a broadly representative body in the Pacific. Even if a new organization could be created that met criteria 1 and 2, an untested organization would not meet criteria 4 and 5 at all and would risk not attracting the support required to meet criteria 3. Its greatest risk, however, would be the potential cynicism and frustration it would breed by those who had already put considerable voluntary effort into existing structures and processes. It would also take us one step backwards in needing to invest in considerable establishment work to ensure it had sufficient interest, representation and credibility – and even then may not succeed.

It is our conclusion, that the international policy environment (considered in Part 2) and the gradual changes which can be seen for people with disability in Pacific Island countries (some examples of which are listed at Appendix VI) suggest the time has come to support the development of a truly indigenous Pacific disability body. *Inclusion International’s* work in the Pacific has helped to bring us to this stage and to make this possible. And we certainly hope that the valuable support *Inclusion International* has provided to Pacific initiatives to date will continue. However, it is our finding that the ‘lead’ organization to take the next steps in improving the position of people with disabilities should now be an indigenous Pacific disability body.

If this opportunity is not taken, NZAID funding (together with other funding) will continue to work on disability issues at the current level, rather than at the many levels required. Supporting an indigenous Pacific body with a clear regional profile and agenda is likely to raise the visibility of disability issues across the Pacific and build on the important country by country work, supported to date. Such a strategic profile will assist communities, governments (in and outside the Pacific), regional and international development bodies to recognise and focus on disability as something that can be worked on at local, national and regional levels.

³⁶ UN ESCAP (2003) *Focus on Ability, Celebrate Diversity: Highlights of the Asia Pacific Decade of Disabled Persons, 1993-2002*, Social Policy Paper No. 13, 2003 (ST/ESCAP/2291), ESCAP, Bangkok

Unfortunately, while NZAID continues to provide regional disability funding to organizations other than one comprising Pacific Islanders with disabilities, a subtle message will also be sent that Pacific Islanders with disabilities and their local supporters are not able to manage and promote this development process. This would undermine NZAID's emphasis on inclusion (see Part 2) in the development process.

As discussed in more detail in the following sections, we are proposing that the Pacific Disability Forum (PDF) should be supported to take up this role as soon as possible, notwithstanding the challenges and risks facing PDF (see Section 5.5) and the time needed to ensure the appropriate inclusive development of such an organization (see Section 5.6).

5.3 PACIFIC DISABILITY FORUM (PDF)

PDF substantially meets most of the criteria identified in the previous section. Its focus on people with disability clearly satisfies criteria 1. Its structure and governance requirements (see, for example, section 10 of the *PDF Constitution*) satisfy criteria 2. The history of the organization's development, interviews with country members, and analysis of its constitution, strategic plan and current membership (see also discussion in Section 5.4 and 5.5) all offer evidence for meeting criteria 3.

The capacity of PDF is yet to be completely put to the test, therefore it is not yet fully established that the organisation can adequately meet criteria 4. It has however successfully undertaken some coordinated advocacy on the Pacific Plan, as well as developed its own strategic plan and constitution. The number of capable individuals and organizations supporting PDF suggest that it may be capable of efficiently delivering regional outcomes on an ongoing basis. Its lack of resources and resulting relatively low profile mean that, in general, it does not yet fully meet criteria 5. There is however some indication of respect by those regional agencies and organizations currently most involved in disability issues in the Pacific, to the extent that PDF's current profile allows. For example, the Pacific Islands Forum Secretariat actively sought co-sponsorship with PDF of the recent Pacific Regional Workshop on Disability (see Appendix VII). As discussed below in Section 5.4, PDF has established the respect in which it is held by its strong strategic relationships with key organisations, such as Asia Pacific Disability Forum (APDF), Disabled Peoples International (Oceania), Inclusion International (Asia Pacific), Pacific Islands Forum Secretariat, Rehabilitation International, and United Nations Economic & Social Commission for Asia and the Pacific (ESCAP) Pacific Operations Centre.

PDF developed from being a Pacific regional sub-committee of *Disabled People's International* set up in 2001 to advise and support DPI Oceania on Pacific issues (see Section 2.3). It has slowly, but sustainably developed since then. Organizational development however slowed significantly in 2004 due to the need for adequate resources in order for it to take its next step. For most of this time PDF has primarily operated as a network, rather than an organization – only really having an existence when it met, generally not initiating programmes in its own right, and primarily focusing on communication and information sharing among its members.

PDF is currently operating between a network and an organization. This is a difficult period of transition in the lifecycle of any group. A network essentially focuses on

communication (and most especially internal communication – which across the Pacific can have challenges of its own). In essence a network only really exists when it is meeting or communicating in some other way (such as email). The identity of the member organizations is primary, and participants loyalties is not so much to the network as to the constituent organizations, and the identity of the network itself is fuzzy, and moves in and out of focus. Indeed there are often advantages to having loose and ill-defined boundaries at this stage of development.

As an association formalizes, it faces a number of distinct challenges. The boundaries and identity of the organization need to firm up. This may include difficult or contentious issues about where to draw the boundaries. There may also be differences about how firm the boundaries should be. The emerging organization needs to establish a clear and distinct identity separate from its constituent members. This frequently requires some members to shift loyalties from their local organization first (and the association second), so that this is at least a core leadership group whose primary loyalty is to the new association. And this needs to be done in such a way as to not disconnect from its constituency – but still maintain strong and accountable links to its membership. So, with PDF, it will also need to nurture a leadership that is passionate about what can be achieved at a Pacific regional level, without losing touch with its in-country bases. The challenges of this transition should not be underestimated if it is to be handled successfully for the long term.

At the time of writing this Report, PDF was in the process of registering its constitution in Fiji. Although the organization has a strategic plan it has been able to meet few of its “Objectives”. Some of the activities which contribute to these objectives have been undertaken with the hard work and commitment of members and donation of resources by some member organizations. However this has been inconsistent to date, for a number of very good reasons. Due to communication difficulties, existing commitments of members and the range of other resourcing challenges faced by disabled persons’ organisations (discussed in Section 4.2), PDF will not be in a position to realistically implement its strategic plan until specific resources are made available.

Just as country-based advocates advise disabled persons’ organisations require an appropriate time frame for development, PDF will also need an appropriate ‘Pacific’ time frame³⁷ for its development path. This was summarized by one PDF member as

“In the Pacific we do things according to our own culture. In Asia organisations are started and they run immediately. Here in the Pacific we give time for the organisation to grow, then crawl, then walk, then run. We must let the PDF grow in its own Pacific time, not Asian or Western time. We need to fund PDF according to its own growth path that is sustainable.”

The seed of the idea of PDF and all it can achieve, needs to be able to take root deep in its own soil, if it is not be blown this way or that by external pressures or donor

³⁷ Edwards Halls (1959) second classic dimension of culture is the difference between *polychronic* versus *monochronic* time orientation. The first refers to an approach that would probably be comfortable in the Pacific, where time is fluid, multiple tasks are handled simultaneously and the schedule is usually subordinate to interpersonal relations. This contrast with the more Western orientation, where the schedule coordinates activities, one task is handled at a time, time is rigid and interpersonal relations are usually subordinate to schedules.

expectations, nor dry up and shrivel when scorched by the first crisis or conflict that comes along. An appropriate timeframe will provide time for the optimal involvement, support and ownership by members. In the Pacific where communications are sometimes difficult and member organizations are at very different points in their development, an organization like PDF will need to actively involve its members in its development. This is strategically important to PDF as one of its most important strengths is its existing strong country-based support. To lose this support would forego considerable capacity and strategic advantage for the organization.

5.4 PDF: STRENGTHS & OPPORTUNITIES

PDF has a history of progressive development (see Section 2.3) which exemplifies the involvement of a diverse group of dedicated people, its stability and its representativeness across a range of Pacific Island countries. Importantly, Pacific Island country disability organizations largely developed PDF together with DPI (Oceania). They have a solid sense of ownership, and strongly support PDF as the disability organization for the Pacific. This broad and deep support can perhaps be regarded as PDF's most important strength.

PDF has a Constitution and Strategic Plan. These documents enable the PDF Executive Committee to implement its Strategic Plan and associated programmes and activities. This is an important and useful delegation as the strategic plan includes the creation of an

“established and efficient PDF Regional Office and Secretariat, equipped with qualified staff that is directed by proven management systems, enabling them to deliver effective services and programs to its confirmed members, towards equalization of opportunities and full participation of PWD's in the Pacific region.”

The other “goals” of the PDF strategic plan are:

- 2). a strengthened advocacy programme
- 3). established, effective and efficient national member organizations
- 4). an established network system (relationships with other organizations), and
- 5). organized service delivery systems.

“Strategies”, describing how these goals will be achieved and “Key Result Areas”, indicating how performance will be measured, are detailed in the Strategic Plan. The Plan also describes the rationale and purpose of PDF, its vision, mission, beliefs and values. Any outsider reading this document could be in no doubt of what PDF is about. Unfortunately, however, the current costing method used would make it difficult to easily fund elements of this Plan.

The PDF leadership is strong and experienced. This includes, but is not limited to, the Executive Committee. A problem faced by the Pacific disability movement in general, however, is that the leaders have often been the same people for some time. The PDF Executive Committee advises that they are conscious of this and believe that there are many people with disabilities throughout the Pacific with leadership potential, but for the support to move into leadership roles. They recognize PDF's responsibility for succession planning. As one leader put it, when discussing possible leaders with

disabilities, “People also need to better understand the *potential* of people with disabilities.”

The current PDF membership in the Pacific appears strong. These members have already illustrated their support of PDF in a range of ways, including:

- unqualified support for PDF as the regional disability organization for the Pacific as expressed in the outcomes of the *Pacific Regional Workshop on Disability*, Nadi, August 2005 (see Appendix VII);
- joint development of PDF’s recent Pacific Plan submission and active in-country advocacy towards the same ends as those expressed in that submission;
- unequivocal support expressed in interviews and workshops held in three Pacific Island countries for this Review, as well as at the Nadi 2005 regional workshop; and
- collaborative engagement in the preparation of and support for the Strategic Plan and Constitution.

The 2005 Annual General Meeting saw the attendance of 13 voting members and apologies from three other voting members.³⁸

Opportunities for future partnerships and support for PDF

There is some interest by international and regional inter-governmental agencies to begin or enhance work in the disability field, but there is a lack of a regional focal point for this work. Similarly, there are Regional NGOs, such as Disabled Persons International, Foundation for the Peoples of the South Pacific International (FSPI), and Regional Rights Resource Team, interested and willing to support and partner with a disability-focused regional organization. The PDF’s country-based support and disability expertise makes it very attractive for partnership work and to attract the necessary resources where they are available. There is also a wide range of other international and regional organisations currently doing little or nothing for the empowerment of Pacific Islanders with disabilities. These organizations are ripe to be lobbied for a more active role in this field, and include the Secretariat for the Pacific Community (SPC), United Nation’s Development Programme (UNDP) Pacific Centre, and the United Nation’s Childrens Fund (UNICEF).

Even before entering into partnerships PDF has strong existing key strategic relationships in the region. These include:

³⁸ Organisations represented at this meeting included: Cook Islands National Disability Council, Disabled Persons Rehabilitation Association Solomon Islands, Disabled Persons International (Oceania), Fiji Disabled Persons Association, Fiji Sports Association for Disabled People, Inclusion International (Asia Pacific), People With Disability Australia, Nofo Mapusua, Nuanua o le Alofa, Papua New Guinea National Assembly of People With Disabilities, Pasefika Network of Women with Disabilities, Rehabilitation International (Asia Pacific), Tuvalu Red Cross, and Vision Pacific. Apologies were received from Te Toa Metoa, Kiribati, Disabled Persons Assembly New Zealand, and Vanuatu Disability Promotion & Advocacy Association. We are aware of other disability organizations which wished to participate, but were not nominated by their government to do so – which was necessary as the travel was funded by the Pacific Island Forum Secretariat workshop held in association with the PDF meeting.

- Inclusion International
- Rehabilitation International
- Disabled Peoples International (Oceania)
- Asia Pacific Disability Forum (APDF)
- Pacific Island Forum Secretariat, and
- United Nations Economic and Social Commission for Asia and the Pacific (ESCAP) Pacific Operations Centre.

The first three of these are members of PDF. At its 2005 annual general meeting, PDF resolved to join APDF as a member. Meanwhile PIFS and ESCAP have shown unequivocal support for PDF. While these relationships are already strong, increasing PDF's capacity will enable these key strategic relationships to be appropriately further strengthened, along with the growth of some new key relationships to assist the organization to meet its advocacy goals.

The *Biwako Millennium Framework* provides the best regionally based advocacy tool for PDF, as all Forum leaders have signed up to its policies and goals. Exploiting the opportunities in the *Biwako Millennium Framework* will require the PDF to build on the advocacy many of its members and allies have already individually undertaken to reach its current political support. There are also other international agreements which the PDF may also be able to draw on in the advocacy process (for example, the Millennium Development Goals, 'Education for All' commitments, the Forum Basic Education Action Plan (FBEAP), etc).

Given, however, that the *Biwako Millennium Framework* was agreed to by Pacific Island countries in 2003 and two years later most Pacific Island governments have made little progress against it, people with disabilities in the Pacific are keen to move on from international commitments to national implementation. There is an important opportunity here for PDF to work with its member organizations in Pacific Island countries to advocate for the implementation of *Biwako Millennium Framework* (and other instruments). Where local laws and policies exist there is often work required to ensure that these are observed, funded and acted upon.

While face-to-face is the preferred means of communication reported to the Review, the PDF Listserv provides a vital conduit for regionally networked advocacy on an ongoing basis. This has already been utilized to good effect (see Section 3.1). A strong regional association, with strong and growing affiliates in each Pacific Island country will be well placed to use the Listserv more frequently and more strategically.

The PDF council has had few (if any) opportunities to meet and debate matters in their own space. Unfortunately, the organization has often had to meet in circumstances where there have been considerable numbers of observers present (such as government representatives, international agencies and donors). These observers have commented outside of these meetings that the PDF appears divided on some of its fundamental policies and approaches – which is what one would expect when it is still in the process of developing positions and its own organizational culture and values. That different views can be openly expressed can be a healthy sign of a democratic and open organization.

PDF Council members do not see any apparent major divisions. They see it as a part of the natural and necessary internal debate that any developing organization creates, as well as the healthy policy debates which most effective organizations encourage to

ensure robust positions. Therefore, an important opportunity which the PDF would be well advised to take up, if and when resources become available, will be to enable discussion and debate in a space of their own – instead of having to behave like ‘tenants’ in someone else’s space, relying on other organizations to bring its members together. (New Zealand Maori refer to *turangawaiwai*, as having ‘a place to stand’, which can be the place an organization can develop, nurture and guard its own *kaupapa* or platform and principles.)

5.5 RISKS AND CHALLENGES FOR PDF

PDF also faces a number of risks and challenges. These are no greater than any other developing organization, and they need to be considered in the context of the organizations strengths (discussed in Sections 5.4 above).

The PDF’s Strategic Plan needs refinement (see section 5.4), but it will only be sensible to do this when the organization has a clear idea of its resourced capacity - as this will be a key determining factor for what the organization can achieve. A further, specific point is that the current format and costings methodology of the Strategic Plan may need to be altered before donors like NZAID are completely comfortable with it as a basis for funding.

If the development of PDF as a formal organisation is rushed, it risks weakening itself as well as potentially losing support from Pacific Island members. In this and other ways, PDF will need to work hard at maintaining and building the strong Pacific-wide network and enthusiasm of its members – not an easy task for even the most mature and well-resourced organization.

The PDF Constitution also requires some further fine tuning. There appears to be some imprecise wording which may burden the organization in the future. The openness of PDF’s membership is a strength and involves some opportunities for the organisation. It promotes an inclusive approach, enabling strong alliance building between disabled peoples organizations (DPO’s) focused on rights and empowerment and service delivery organizations with similar ends in mind. The potential risk to be born in mind, however, is that not all potential member organizations hold the empowerment of people with disabilities as their highest priority. Some organizations may be able to meet the criteria for membership, but aim more to protect, pity or even institutionalize people with disabilities. This, of course, would undermine the rights-based approach which PDF is working towards. Although this risk is not immediate (given the nature of current PDF membership), it is better to develop strategies to prevent such tensions arising ahead of time, rather than try and resolve such delicate matters in the middle of a major crisis or destructive dispute. A first step to mitigating against this risk is to clearly identify and agree on what are the organisation’s ‘bottom lines’ and explicitly consider how can these be effectively nurtured, guarded and protected.

The converse, and more immediate, risk to PDF is its potential for excluding allies and supporters (individuals and organizations) who could make significant positive contributions as members. There are many family, carer, and service provider organizations in Pacific countries which ought to be included in the PDF membership. Currently the PDF Constitution allows any of these organizations and individuals to join, but one vote is allocated to each country. Currently these votes are mainly held by DPO’s. In-country promotion (as well as some constitutional refinement to create a

mechanism by which a vote is allocated among various members from a single country) to promote the inclusion of those who support equity and empowerment of people with disabilities. The desirable balance between votes of country and regional organizations might also be worth reviewing.

PDF has no track record yet in delivering any substantial regional outcomes that show evidence of operation in a range of countries, and achieving broadly agreed output(s) (see Section 5.2). Provision of resources may alter this. Nevertheless the organisation's inexperience (notwithstanding the capacities of individual members) means that it will be important that PDF sets its regional objectives and project deliverables initially at modest and achievable levels, and build from there.

The profile and respect with which PDF is held is currently limited by its capacity and visibility. Its volunteer members have already succeeded in gaining a significant profile with, and the respect of, most key regional organizations and inter-governmental bodies. Moving beyond this core group of stakeholders, however, will represent an important opportunity and challenge for the future of PDF.

There are some key developmental factors which the PDF Council has not yet reached agreement on. In fact agreement has been reached on an impressive number of matters, given their limited and infrequent meetings that have been possible to date. There are however important and necessary decisions required, before which, organization development would be premature.

Even though the Executive has the mandate to go forward and implement the current Strategic Plan, it will strengthen the organization if the next steps are only set in place after communication (and preferably) consultation with the membership – to ensure widespread understanding and commitment to these crucial initial programmes of the organisation. Moreover, it is good practice for any organization implementing a strategic plan to report back and consult with its membership, particularly during times of significant change or growth. Consultation opportunities include imminent decisions on:

- which country the secretariat will be located in (it is currently expected to be in Fiji, but the decision may be contentious and thus probably needs to be made in an open, well communicated way);
- the Executive Officer (and any other staff) job descriptions;
- key governance and management operating procedures;
- identification of and agreement on the first clear, focused project for PDF which is achievable and able to be readily reported on to the donor's satisfaction;
- a refined Strategic Plan, matched to likely available resources; and
- negotiations and agreements with donors (including NZAID) on which aspects of the Strategic Plan they are able to fund; etc.

Although the current PDF Pacific-based membership is broad and strong, as indicated by organizations participating in annual general meetings and related processes, they have not moved to the next stage of paying membership fees. At the 2005 Annual General meeting members were given until 30 September 2005 to pay their FJ\$50 membership. The lack of Pacific Island financial members was raised as a factor of concern from at least one member. Although it may be desirable for the organisation to be able to show a substantial paid membership from its Pacific Island country constituents, the collection of money from members is not necessarily the only

indicator of constituent support. In fact, the membership exists, is documented, and how that is managed is largely an internal PDF matter. Thus the collection of membership fees is only a small and internal challenge for PDF, given its constituent support is illustrated in other ways (see Section 5.4), especially as one likely factor is the difficulties of transferring small amounts of money of different currencies around the Pacific – especially ahead of some basic administrative systems being set up. Nevertheless it is an issue that PDF needs to address.

There is a strong recognition that on-the-ground services are the urgent need for Pacific Islanders with disabilities (see Section 4.4). An organization like the PDF will be unable to directly deliver such services, as would any similar regional organization. Although it will be able to strongly advocate for these services and may play a role in facilitating their provision. This is a different focus than that of the work of *Inclusion International*, which as well as supporting regional communication and national surveys has also been able to facilitate some direct, though still somewhat limited assistance, such as donated aids and equipment and organization of other resources and services discussed in Part 3 and Appendix VI. Before the current Pacific Regional Disability project, *Inclusion International* and associated groups were also involved in some other direct forms of assistance, including support for the building of specialist disability centres (Section 2.3). The risk inherent in PDF's advocacy focus is that if services, support and equipment do not soon follow then it may be seen as ineffective.

Most regional NGO's have to confront the massive resource implications of building and maintaining strong linkages throughout the Pacific. Communications are expensive whilst travel is also very expensive in terms of both time and money. Existing regional organizations recognize that these two items are a significant element of any regional budget and PDF will need to budget accordingly.

Existing regional organizations have provided a wealth of other information regarding the risks and challenges they face. Some of those risks, which PDF is also likely to face are captured by advice and suggestions given in good faith by regional NGO's when asked about challenges that could lay ahead for similar regional NGO's:

“There are 2 key issues: (1) clarity of mission and vision throughout the organization; and (2) organization sustainability. Achieve the first, then you need to ensure sustainability of the organizations activities which work toward that vision. You need to get and maintain people's buy in and support and commitment to make your mission happen.”

“You need to ensure good governance machinery. And when operating at a distance you cannot just assume that the governance model is operating well. You just must work hard and check that it is working for this organisation, its board members, its members, and staff.”

“You must remember that you cannot control who comes on, this goes back to the quality issue of the board and unfortunately this can make or break the capacity of the organisation's board.”

“You definitely would need someone who everyone respects and trusts as head of the secretariat... It has to be someone who is a very good communicator.”

“Sometimes things crumble or lose momentum because they lose good leadership, and thus confidence of the members and other stakeholders.”

Communication is extremely important with your network partners. And they will need to agree [on a shared vision and leader].”

“One of the downfalls of these Pacific wide networks is lack of monitoring of the capacity of the organisation. The board is often unable to genuinely monitor what the secretariat is doing.”

“They might be good advocates but might not necessarily be able to manage, attract funds, report etc. Organisations whom we work with are often asking for organisation capacity building as their own sustainability is often at threat, let alone the cause that they work for.”

“For the development of a new organisation like this one, you would need to have someone working in an established NGO regional organisation to ensure they have the capacity, and to contribute and work in a good governance way.”

None of these risks or challenges is a reason for excluding a key role for PDF. Indeed most would apply to any regional organization in the Pacific. But these risks and challenges are real and they must be addressed, especially during a period of great internal change and development. The organization’s clear ability to recognize many of its own risks and challenges bode well for its ability to reflect, learn and improve, and hence build a strong and sustainable future for itself.

5.6 RECOMMENDATIONS FOR THE NEXT FIVE YEARS

At the beginning of this Part, we summarized our findings from the document review and consultations that the key strategic priorities for action at this time in the Pacific for people with disabilities centre around four areas:

- basic awareness raising and advocacy cannot be stressed enough as a high order need which will create the receptive environment required for other change;
- activities supported by the NZAID Pacific Regional Disability Programme and its philosophy must gain leverage over other resources as well, if the ambitious objectives of poverty reduction and social inclusion are to be realised in any meaningful way;
- strong disabled person’s organisations (DPOs) at a national level need to be supported to take up regionally and locally identified needs with appropriate local application; and
- support and resources will also be required at a regional level to enable this necessary in-country work to occur.

The NZAID funding programme for Disabilities, a sub-programme of their Pacific Regional Health Programme, (see Appendix VIII) may provide funds not exceeding NZ\$300,000 per year for the next five years. We have concluded that the most strategic use of these NZAID funds in targeting the above four areas will be built around offering development support and ongoing core assistance to secure and strengthen an effective regional disability organization in the Pacific. Such an organization could be directly involved in awareness raising and advocacy work itself across the Pacific, as well as providing resource material for and supporting the development of strong disabled persons organizations at a country level. One of the specific areas it will need to tackle is the failure of many donor policies and approaches to adequately recognize and help to address the position of people with

disabilities in the Pacific. Our assessment, outlined in the previous sections, leads us to recommend that PDF be the organization supported to build on its current foundations to undertake these roles. We also propose that small seeding and capacity-building grants be available to assist in the establishment and/or development of selected country-level disability person's organizations in the Pacific.

In addition we propose that NZAID itself needs to ensure that on an agency-wide basis, its own policies and plans appropriately recognize and help address the position of people with disabilities in the Pacific (for example, in its Bilateral, Regional and other specific programmes, such as the Voluntary Agencies Support Scheme). We also propose specific initiatives for an inter-governmental disability focal point in the Pacific and for targeting of child-related funding to support early identification and intervention for children with disabilities.

Finally we also propose that in the next year or so funds be made available for various Pacific Island countries to continue and complete disability identification surveys or similar awareness-raising initiatives, such as those initiated under the *Inclusion International* project.

The findings of this Review cover a wide array of issues for people with disabilities and their organisations. The specific recommendations detailed below do not address all of these issues individually. Taken together, however, we believe these recommendations can strategically respond to or contribute to all of these issues over time.

Potential PDF work

Although commissioned by NZAID, it is our hope that this report should also be an important resource for the Pacific Disability Forum and could be used as a basis for and in support of its negotiations with a range of donors.

The PDF's first order of business, upon securing funding, will be to establish itself fully as an organization. A suggested approach for this is set out below in this section.

Once established it would be useful for the organization to define one or two specific and discrete projects. These will need to be agreed with the PDF Council and NZAID as the donor partner. The commencement of specific projects (depending on the particular areas negotiated) can be expected to further build the support of the PDF among its members, supporters and other key stakeholders.

The PDF strategic plan (discussed in Section 5.4) already identifies several areas of work for the organization. Although a quite focused strategic plan, it still may be somewhat ambitious and could be usefully refined with respect to timeframes and capacity, as a developing organization can risk taking on too much too early. Further, despite the plan having been developed in consultation with the PDF Council, its author and other members suggest that there is a need to revisit the plan with the full Council to ensure full and ongoing ownership and make any necessary refinements or up-dates. This has not been able to occur to date, due to insufficient resources.

PDF will always have more opportunities for work than it can possibly deliver on. Therefore another strategic opportunity which should be taken up is the maintenance and development of key strategic relationships. The organizations which are strong in the Pacific, with which PDF already enjoys key strategic relationships include: Pacific Island Forum Secretariat, ESCAP Pacific Operations Centre, Inclusion International

and DPI (Oceania). To maximize its impact and the benefits of its work, PDF may also usefully develop some additional key strategic relationships with some other organizations with an interest in the area of disability, such as Foundation for the Peoples of the South Pacific International (FSPI), International Labour Office (ILO), and the Regional Rights Resource Team.

Priorities for NZAID funding

As the NZAID Regional Pacific Disability Programme is focused on empowerment of Pacific Islanders with disabilities and reducing the inequalities which they experience, it is our assessment that the Pacific Disability Forum is the most appropriate indigenous Pacific organization sharing these objectives and with the potential to act as the lead organization to carry them forward in the current Pacific context.

There are three broad areas of PDF work requiring funding:

- 4) the intermediate next phase of PDF's development as an organization (Stage 2);
- 5) aspects of the PDF strategic plan; and
- 6) provision of small seeding and capacity-building grants to country-based disabled people's organizations.

Recommendation 1: NZAID negotiate with PDF to provide core funding as a strategic regional partner in the disability field in the Pacific, to meet agreed strategic objectives and channel funds to country-based disabled people's organizations working on similar objectives.

This funding might be initially provided for a short term contract period, but should quickly move onto a rolling 3-5 year strategic partnership, once a realistic level of resourcing and organizational capacity to deliver identified outcomes has been established.

Stage 2: Fully developing PDF as a Pacific regional organisation

The first stage of establishing PDF as an effective and functioning network has been remarkably successful, especially considering the lack of resources available to support this process to date. PDF members have identified the next step as Stage 2: Fully developing PDF as a Pacific regional organization. Stage 2 will give PDF the opportunity to create the solid base required, as it makes its transition from a network to an organization, before it is required to deliver on specific project outcomes. Most organisations do not have the opportunity to develop like this and often suffer for it in the long term.

It is our assessment that Stage 2 of PDF's development will be best implemented with the assistance of a skilled consultant working directly to the Executive committee. Included in the work that the consultant will carry out for the Executive will be the important task of keeping the membership informed of developments during this period of growth and consolidation. It will be worth investing in and ensuring *deeper roots* for the organization, as it makes the difficult transition from a network to an organization in its own right, fully owned by people with disabilities and their supporters across the Pacific. The resources proposed in Stage 2, also mean that overall the necessary preparatory work can happen faster and more systematically than having to rely completely on volunteers to do this work, while nevertheless

ensuring the work remains clearly under the PDF Executive Committee's control and direction.

Some of the limited literature on such associations suggests that their effectiveness will depend on achieving sufficient '*autonomy*' (which is in turn determined both by their resourcing, and other factors such as their political credibility) and '*representativeness*' (which is in turn determined by how the organisation ensures both effective accountability and mandate)³⁹. The most common activities of such organisations are information dissemination, advocacy, networking, research and policy development, followed by membership support (training & capacity building), and monitoring⁴⁰. Or, as the Australian Council of Social Service⁴¹ has described these tasks:

- Representation and communication
- Policy research and development
- Policy advocacy, and
- Sector development (capacity building).

As we have noted above, the difference between a 'network' and an ongoing regional association is that a network is mainly focused on communication tasks, and work in any of the other areas is largely incidental or ad hoc. An ongoing regional association generally needs the capacity and infrastructure to work across all four areas, as well as a sound basis for achieving needed resourcing and political credibility, and a representative structure which ensures accountability and mandate. These are difficult to achieve even on a national basis; much more so on a regional level across the Pacific, with its considerable diversity, and its expensive and difficult transport and communications.

PDF's greatest strategic advantage is its support by key stakeholders in Pacific Island countries. Stage 2 will foster and build on this support. Keeping members informed on the range of issues still requiring work (see Section 5.5) will strengthen the organization's links with its members, also mitigating some of the risks it faces.

In particular, although the low rate of paid-up membership is not currently a limiting factor for PDF, the organization will need to work hard during Stage 2 to secure paid up memberships from all currently unfinancial members. This will require ongoing genuine engagement with members, provision of evidence that paying membership to PDF is worthwhile and promotion of membership to potential PDF members.

The work to be undertaken in Stage 2 involves a range of logistic and organisation development tasks, including:

- refining and registering the Constitution;
- establishing a PDF bank account;

³⁹ Industry Commission (1995) *Charitable Organisations in Australia* (Report No.45), Australian Government Publishing Service, Melbourne

⁴⁰ Rose Melville (1999) "Australian Peak Bodies and the Market Policy Culture" Paper presented at *National Social Policy Research Centre Conference: Social Policy for the 21st Century: Justice and Responsibility*, 21-23 July 1999, Sydney

⁴¹ Australian Council of Social Service (1991) "Review of Funding for Secretariats of National Peak Organisations: Submission to the House of Representatives Standing Committee on Community Affairs

- refining and updating the Strategic Plan, including its budget;
- arranging Executive meetings – say, three teleconferences (2 hours each) and one face to face meeting (1 week);
- PDF representative work (by Executive or nominee) as required (for example, see representation and advocacy opportunities identified below);
- commence development of a Board and management manual, (for example Executive and employee duty statements, Executive and Council operations procedures, Human Resource policies, etc);
- creation of Membership policies, procedures (or at least the articulation of their principles) and establish register of financial members;
- all necessary preparations for the next AGM/regional meeting (ie, seek agreement on key objectives, workshop agenda, resource people, budget, allocation of responsibilities, etc);
- organise auspice of the organisation within an established regional NGO (see Section 5.7) and negotiate auspice agreement;
- agree and finalise Executive Officer and any other key job description, contract and recruitment processes;
- recruit Executive Officer ;
- negotiate (Stage 3) funding agreement with NZAID; and
- regularly communicate developments on all of the above activities to the membership and undertake two-way consultation where possible and appropriate.

Stage 2 can be considered complete when the above tasks have final outputs reported against them. Although there is some flexibility regarding the completion of the policy and procedure development tasks (governance, management and membership) the other tasks will have clear and conclusive outputs.

These tasks could largely be organised by, if not substantially carried out by the contracted consultant. However, these and all other tasks would need to be carried out under the effective supervision and direction of the Executive committee. To ensure openness and transparency, a select tender process could be conducted for the potential consultant (whereby at least three consultants are chosen to tender for the task, and are asked to: set out how they would assist the PDF in a predetermined selection of the above tasks; and provide evidence of their understanding of and commitment to disability issues in the Pacific; and capacity to work to the direction to a representative committee.)

If at all possible a draft of the funding agreement would be discussed with the new Executive officer after he/she has been selected. This is important as it is the Executive officer who will be responsible for directly implementing the agreement and therefore will need to most closely understand the agreement, its key requirements and flexibilities, along with the PDF Executive – who will be responsible for ensuring all its requirements are met and outcomes achieved.

We are convinced that face-to-face and teleconference meetings of the PDF Executive committee will be crucial to the completion of Stage 2. Particularly during the face-to-face meeting action planning, commitments to undertake tasks and agreements on a

range of matters will need to be reached (eg employment, budgets, advocacy activities, regional meeting and strategic relationships).

Volunteers working for PDF (in particular the PDF Executive Committee) have brought the organization a long way to date. However, these people are busy with work and family commitments. Also, the fact is, having a disability can additionally limit one's available time. Mainly for these reasons the PDF development process has slowed down over the past year or so. It is now an appropriate time to invest some realistic resources to ensure timely implementation of Stage 2. Actual budgets would, of course need to be negotiated between PDF and NZAID, and not all contingencies or costs can be known in advance of certain decisions (such as location) being made. However, we believe, on an indicative basis that it should be possible to undertake the necessary tasks outlined above for Stage 2 within the following resources:

Expenditure Type	Amount(NZ\$)
Consultant working directly to PDF Executive Committee 35 days @ (\$800/day and sub-contracting + expenses)	35,000
Office space (if required), Administrative, postage, communications and related costs for the project officer	15,000
Executive committee Teleconferences and Nadi meeting	16,000
Travel costs for PDF representational work (as required)	6,000
Recruitment of Executive Officer	3,000
Purchase of office equipment and assets - including Information Technology (may be carried over to Stage 3)	5,000
Contracting external expertise (governance and management manual development and Executive governance training)	20,000
TOTAL	100,000

Changing priorities and unexpected costs may result in the need to move expenditure among items (in a budget neutral way). Some funds may also need to be carried forward into the 3rd stage to allow for the phased continuation of some of this work.

The Expenditure Item 'travel costs for PDF representational work (as required)' may contribute to a range of upcoming representation and advocacy opportunities, such as:

- *Disability: A Global Perspective on Rights to Education and Livelihoods*, being organised by UNESCAP and Leonard Cheshire International on 17-18 October 2005 in Bangkok⁴²;
- *Workshop on the implementation of the Biwako Millennium Framework: Development of National Plans of Action on Disability*, being held by UNESCAP on 19-21 October 2006 in Bangkok;
- *APDF meeting and regional conference* in July 2006 in Melbourne, and

⁴² <http://v1.dpi.org/lang-en/events/details?page=21>

- *Education World Conference* being held by International Council for Education of People with Visual Impairment on 16-21 July 2006 in Kuala Lumpur.⁴³

Recommendation 2: Funding for PDF be negotiated initially at around NZ\$100,000 to implement Stage 2 over a 12 month period, thus establishing it as a regional association able to deliver advocacy, information and capacity building outcomes and represent Pacific Island country disability issues.

Stage 3: Core Operations and projects

The beginning of PDF's ultimate stage in development should be marked by the following activities:

- convening of the next AGM/regional meeting (3-4 days, one representative per member country);
- modifying and ensuring ownership of the Strategic Plan for the organisation and its membership; and
- putting administrative and financial systems in place, including processes for international transfer of funds.

The existing Strategic Plan (as refined by the Executive Committee in Stage 2) will be sufficient to use as the basis for negotiation of a funding agreement with NZAID. This funding agreement will however need to be flexible enough that it can accommodate member development of the Strategic Plan. Thus agreement with NZAID on the aspects of the PDF Strategic Plan which will be resourced over the ensuing four years will include the core costs of operating, managing and governing a regional disability association. It should also include provision for tangible and discrete PDF advocacy and capacity-building projects to be undertaken over time.

It is anticipated that the core costs of operating a regional disability peak body will require a budget along the lines of the following:

Expenditure Type	Amount(NZ\$)
Salaries (Executive officer and policy/project assistance)	80,000
Staff mentoring, training and development	10,000
Rental of office space	20,000
Office expenses (stationary, postage, communications, etc)	30,000
Executive (and/or sub-committee) teleconferences (12 hours/year) and one face-to-face Executive meeting	20,000
PDF council meeting (1 per year)	22,000
Travel costs for representational and advocacy work	6,000
Bookkeeping, accounting, and audit	8,000

⁴³ <http://www.icevi.org>

Discrete advocacy/sector development Project(see Rec 3)	50,000
TOTAL	247,000

The proposed auspice of PDF's office by an existing regional organization (see Section 5.7) will mean that most, if not all, of the Expenditure Items 'Rental of office space' and 'Office expenses' etc could be paid as a fee to the auspicating organisation. The amount for 'Office expenses' allows this to cover all stationary, phone/fax/internet usage as well as some basic administrative support staff time.

Ideally the PDF Executive will also support the establishment of mentoring for the new Executive Officer (discussed in Section 5.7). The breakdown of this expenditure will be determined in consideration of the skills and support needs of the staff.

The discrete and tangible project work of the organization (referred to in the above budget) may grow in size and capacity with the growth of the organization. For example, in its first year of full operation the PDF may choose to focus its activity on building relationships and raising its profile towards partnership opportunities with regional NGO's, UN bodies and Council of Regional Organisations of the Pacific (CROP) Agencies. Other potential discrete projects suggested by PDF members and stakeholders (some of which are in the current PDF strategic plan) include:

- Partnering with country-based disabled persons' organisations to advocate for *Biwako Millennium Framework* implementation as required in each country;
- Provision of training and development for disabled persons' organisations on advocacy;
- Provision of training and development for disabled persons' organisations on NGO management, governance, finances, etc;
- Research and identification of discriminatory policies, practices and programs and advocate for change;
- Research the design and provision of good practice service delivery systems and facilitate their implementation; and
- Participate in international agreement/instrument development;

Due to the limitations on NZAID disability programme funding, expenses for this aspect of PDF work would be expected to be limited to about NZ\$50,000 per year.

This funding may be used to fund a range of expenses towards these projects including:

- project officer and/or contractors with relevant expertise;
- staff to support the Executive Officer in organization's core operations if the Executive Officer is involved in project delivery;
- travel throughout the region;
- stakeholder meetings and workshops;
- additional office and administrative overheads; and
- resource material, training materials, etc.

Recommendation 3: NZAID negotiate ongoing partnership funding for PDF core costs of around NZ\$250,000 per year (including around NZ\$50,000 for discrete regional advocacy and capacity-building project/s).

Resourcing Country based Disability NGO's

Country-based Disabled Peoples Organizations (DPO's) not only require skills and technical capacity building support from PDF, but direct resource provision themselves (see Sections 4.2 and 5.1). Some small grants of approximately NZ\$10,000 would assist the establishment, development and sustainability of organizations at the country level, without whom much of PDF's work would be very difficult.

Consistent with NZAID's aim to have money distributed to country-based organizations by a Pacific-based organization, this will promote greater Pacific ownership and local responsiveness. A key benefit for NZAID of stronger local disabled persons' organisations will be having independent advocates working in-country to ensure that bilateral programme funds (and other assistance) is spent to the best effect. This will also assist in promoting congruence between different NZAID programmes in-country (eg education, health, governance and human rights).

Although only a small amount of money, it is suggested that these funds be targeted at those organisations which have formed, but are having trouble attracting the resources to fully establish themselves or to effectively implement strategies. Such funds may help strengthen an organization to enable it to secure more substantial and/or longer term funding from other sources (including national governments, other NZAID funding streams or other donors), by providing an opportunity for the organization to establish its local credibility and 'prove its worth.' The funding may cover or contribute to:

- Office space and equipment (including Information Technology);
- Data collection work (see Sections 3.3 and 3.7);
- Awareness raising campaigns;
- Locally purchased training;
- Strategic advocacy campaigns; and
- Membership growth and development.

Section 4.2 contains further details of potential country-level work for disabled person's organisations.

To ensure that there are not conflicts between the allocation of funds to members and PDF's governance process, it is suggested that PDF establish an independent subcommittee which reports its findings to the Executive Committee (possibly chaired by an Executive Committee member). It might call for short funding requests of 1-2 pages from disability organizations in Pacific Island countries. The criteria used to assess the applications would need to be developed in consultation with disabled persons' organisations and could include such elements as:

- Is the organization focused on empowering people with disabilities and reducing inequality?
- How will the funding strengthen the organization's ability to do its work?
- How will the funding improve the lives of people with disabilities?
- Does the organisation have evidence of support from people with disabilities and is the organisation controlled by people with disabilities, and developing leadership of its members and others with disabilities?

- Is the organisation inclusive of a wide range of people with disabilities, including groups that may be overlooked (such as women & girls with disabilities, people with intellectual disabilities, etc)?
- Does the organisation have a viable plan for its future development?

Recommendation 4: NZAID allocate PDF around NZ\$50,000 per year to provide seeding and capacity building funding to disabled persons' organizations in Pacific Island countries on agreed criteria.

5.7 POSSIBLE PDF AUSPICING ARRANGEMENTS

In determining a possible auspicing arrangements to house and support PDF possibly during Stage 2 but certainly through Stage 3, two organizations met the requirements, but in different ways. The criteria were for an organization that is:

- 1) very well governed and managed (and able to role model good practice in these areas);
- 2) regionally focused, and able to contribute practical experience of working regionally;
- 3) working in areas congruent with a rights-based approach for people with disabilities ;
- 4) able to provide support and encouragement to the PDF without controlling it;
- 5) able to provide office space, administrative support, telecommunications and related office resources for a reasonable fee;
- 6) well respected by donors, international agencies and governments.

Regional inter-governmental and UN bodies (for example, Pacific Islands Forum Secretariat, Secretariat of the Pacific Community, United Nations Economic and Social Commission for Asia and the Pacific, and United Nations Development Programme) were considered for this role. Initial enquiries, however, found that they would not be able to provide the services and office space for the 'reasonable fee' (criteria 5), due to the higher overheads these organizations operate with. Further, the very different governance and management models these organizations use for decision making would not necessarily provide the right environment for the development of PDF as a good practice non-government organization.

Of the two NGO's considered for the role, the Pacific Island Association of NGO's adequately met the criteria, while the Foundation of the People of the South Pacific International (FSPI) was found to best meet all criteria. In particular their good governance and management is extended by their hands-on in-country development work in this area (criteria 1 and 4). Their work with Pacific Islanders promotes empowerment and equality in long-term sustainable ways which is consistent with the approach PDF will have to take (criteria 3). The high esteem with which FSPI is held by those operating in the region will also enable PDF to be recognized as a good practice organization with respect to delivering regional outcomes (criteria 6). FSPI uses a slightly different regional approach to PDF, utilising partner organizations rather than a network of members (reflecting the development rather than association/representative role that FSPI plays).

The Regional Rights Resource Team (RRRT) was also considered a potential auspicing body. It strongly fits criteria 3, given its rights focus. RRRT is "semi-

autonomous”, in that it is an arms-length project of UNDP, and with its own board of governance. RRRT takes a slightly different approach again to its regional work, using partner organizations not a network of members (reflecting the development rather than association/representative role they play). This means that it may work in a different way than PDF does (criteria 1 and 2).

The management of PIANGO, FSPI and RRRT were all willing to discuss possible auspice arrangements with PDF. All are based in Suva, Fiji.

Recommendation 5: PDF Executive negotiate supportive auspice arrangements with an appropriate NGO with a view to securing the highest quality auspice arrangement with one of these organizations, during Stage 2.

The aim for PDF in this auspice arrangement should be that it can operate economically (by purchasing portions of a range of office services and resources) and effectively (through good leadership on regional governance and project delivery). It will be important that PDF maintains a long-term strategic relationship with all of the organizations considered as possible auspicing bodies (and a number of other significant stakeholder organizations identified elsewhere in this report) as there are opportunities for synergies and partnerships with all of them on specific issues.

Ideally the auspicing organization could seek extra resources from another donor to assist in its initial supportive role with the PDF. This is not a necessary condition, however, as the PDF budget provides for some mentoring and development of its staff.

In the event that the PDF is located in Suva, a plan should be put in place to enable, at least alternate, annual general meetings to occur in different member countries on a self nominated basis (as local organizations may be required to assist in organising the regional meeting). This would mitigate some of the trade-offs involved in locating the office in Suva, build greater support and visibility amongst the membership and provide increased development opportunities for people with disabilities who often do not benefit from opportunities to travel to regional meetings and workshops. The costs implications would need to be managed within available funds.

Mentoring of PDF Executive officer

Assuming that the PDF Executive will prefer to employ a Pacific Islander with a disability, it may turn out that the right person does not have all of the wide range of experience and skills desirable for leading a regional association - given the current lack of opportunities available to Pacific Islanders with disabilities. Although it would be appropriate to choose someone on this basis, it would be remiss and detrimental to PDF for the Executive Committee not to also institute the necessary support structures to ensure the Executive Officer might appropriately develop into their role.

Often experienced executive officers receive formal mentoring as part of their ongoing professional development, and this is increasingly considered good practice for NGO managers⁴⁴. Frequently an executive officer needs to seek guidance or support on matters which he/she will not always wish to raise with his/her board of

⁴⁴ Kura Geer-Watson (2002) *Mentoring: A Discussion for those Employed by or Involved in the Voluntary/Not-for-Profit Sector*, New Zealand Federation of Voluntary Welfare Organisations, Wellington <http://www.nzfvwo.org.nz/files/file/mymentor.doc>

governance in the first instance. Also the board may not always have the time or skills to properly assist. Such challenges can include: staff performance, time management, planning, other management and leadership issues.

Mentoring may come from a range of sources. If the skills and capacity exist within the auspicing organization it may be possible to purchase some mentoring or professional supervision support for the new Executive Officer, as a part of the overall purchase of office and other services. It may be easier to create a formal relationship with an external person with the necessary skills and experience with whom both the Executive Officer and the Executive Committee are comfortable. The skills and knowledge of the mentor will depend on the needs identified by the Executive Officer. The process usually involves fortnightly or so debriefing meetings with the mentor.

Recommendation 6: After appointing the Executive Officer a representative of the Executive Committee should be appointed to work with the Executive Officer to contract formal mentoring support from outside of the organization.

5.8 LEVERAGING OTHER RESOURCES

NZAID Pacific Regional Disability Programme has a very ambitious agenda with very limited funds. It will only be possible to make a significant impact on this agenda if regional funds are used to maximise leverage over other funds and resources, and if other resources available to NZAID are also deployed in a way that is consistent with the approach of the Pacific Regional Disability Programme. Other funds and resources include: other NZAID Pacific regional programmes, NZAID bilateral programme funds, specific NZAID funding programmes (such as Voluntary Agencies Support Scheme), and less formal funding arrangements (for example, Head of Mission funds, etc), Pacific Island Country national government priorities and resources from other donors.

The proposed priorities are designed and put forward with this in mind. For example, strengthening national disabled peoples organisations is likely to improve national advocacy, public visibility of disability issues and awareness of needs in government plans etc. This should then influence national government priorities, including plans for Sector Wide Approaches as well as other bi-lateral funding which national governments negotiate with NZAID and other donors.

The lack of regional coordination of responses to disability needs is a problem identified by many across the region. Improved coordination could be expected to result in more effective use of the limited funds in this sector. Such greater coordination could best be implemented through the creation of the regional focal point for disability proposed. This would promote the coordination of the wide range of disparate activities occurring at a regional and national level. Further, it would provide for an official mechanism to promote appropriate activity where regional inter-governmental bodies, international agencies and national governments are less involved.

As well as the work proposed for the Pacific Disability forum (PDF), an appropriately located regional focal point within a regional inter-governmental agency could have the status and capacity to promote such activity at a governmental; and inter governmental level. An inter-governmental regional focal point for disability would

be highly complementary to the advocacy and development work of PDF, particularly given the more activist role that an NGO might play compared to a position in an intergovernmental agency. The mutually reinforcing complementarities would therefore likely see gains for Pacific Islanders with disabilities which would not occur if the PDF or a regional inter-governmental focal point alone were funded.

Given the coordination and political nature of a regional focal point for disability it would be crucial that it be placed in an agency where it is possible to:

- Drive attitudinal change at a regional, political and national level;
- Play a strong (albeit diplomatic) hand in ensuring governments take their responsibilities under the *Biwako Millennium Framework* seriously;
- Impel regional and international agencies to raise disability as a priority in their own work and through regional and international agreements (eg Pacific Plan and Millennium Development Goals);
- Consult, identify and collect existing information, research and data on disability in the region to be accessible to those working in the field; and
- Partner with PDF where possible to meet mutual objectives and promote change at all levels.

This style of work would be best located in the Pacific Islands Forum Secretariat (PIFS). The position would also be supported and provided with the greatest opportunities to do this work given that PIFS is one of only two regional or international agencies currently appearing to undertake any significant work in the area. A well implemented focal point would also require NZAID to use its position in existing regional forums, potentially draw on its funds outside of the disability programme and urge other development agencies to also raise the profile of disability in their own development work.

Recommendation 7: The Pacific Islands Forum Secretariat (PIFS) be supported to create a position of regional focal point for disability, (1) politically through New Zealand’s diplomatic relationship with PIFS, and (2) financially through NZAID’s financial relationship with PIFS.

Leveraging other resources will be supported if NZAID actively works to remove disability ‘denial’ from across its policies and programmes. In the same way that removing gender ‘blindness’ improved the position of women in development.

Currently little regard is paid to the needs of people with disabilities when mainstream funding is being secured (See Section 2.3). In some instances improvements could be made merely by adding a question in the selection criteria: ‘What is this project doing to empower and/or assist people with disabilities?’ Sector Wide Approaches can still respond to national government priorities, without denying the existence of people with disabilities. For example, it is difficult to imagine how one could achieve ‘education for all’ if it doesn’t involve specific plans for including people with disabilities.

Recommendation 8: NZAID review its approach in negotiating bi-lateral programmes (as well as less formal funding windows) in the Pacific (and elsewhere) to ensure it promotes inclusion and reduces inequalities faced by people with disabilities

Recommendation 9: NZAID commit to this strategic approach from 2006 and raise the issue with other regional donors and at OECD DAC and in related development forums with other development partners.

Recommendation 10: NZAID ensure policy and guidelines currently being revised for VASS (and other funding windows) pro-actively promote inclusion of, and reduce inequalities faced by, people with disabilities.

The lack of identification of disability (followed by the provision of basic outreach support once identified) remains one of the greatest barriers to equity for people with disabilities in the Pacific (see Section 3.3 and 3.7). There are considerable long-term benefits to implement early identification and intervention for children (see Sections 2.2 and 5.1). Although not the specific focus of this Review, this need cannot pass without comment. It could be the useful focus of specific work within NZAID (and other donors in the Pacific) to identify systemic ways of addressing this need.

Recommendation 11: NZAID give consideration to current child-focused funding playing a role in supporting early identification and intervention programs for children with disabilities with a view to their continuing access to education.

There is extensive work currently underway at a global level to understand the best ways to collect data on disability. This information is currently not available to organisations in Pacific Island countries wishing to undertake data collection, despite the existence of relevant technical expertise at the Secretariat of the Pacific Community (SPC) (see Sections 3.3, 3.6 and 3.7).

Technical expertise may also exist for SPC to implement other development work such as awareness raising and empowerment for people with disabilities.

Recommendation 12: NZAID request the Secretariat of the Pacific Community (SPC) to target disability issues in its technical development work, in particular SPC's Demography Programme, to provide technical advice, training and support for disability data collection by government statisticians and NGO's.

We have already noted (in Sections 3.3, 3.6 and 3.7 and Appendix VII), the impacts achieved by the disability identification surveys initiated by *Inclusion International*. Especially given the widespread lack of awareness of disability issues in the Pacific (see Section 4.1). In particular, when well implemented with adequate local support and commitment, it can be very useful for ongoing advocacy, service delivery and development for people with disabilities. In a number of Pacific countries, the national disability identification survey has not yet been completed. Notwithstanding some refinements called for in Section 3.7, completion of these national disability identification surveys would be a very effective use of some of the available regional funds. On the current indicative funding levels, funds should be available within the first 12 months or so that could be used for this purpose. Even if *Inclusion International* continue to be contracted to assist in this work, it is important that these are negotiated and recognised as priorities on a country-by-country basis. Initial proposals could be invited from the relevant coordinating committees in each country.

If continuation and completion of national disability identification surveys is not considered a priority within a particular country, these funds could be made available for other disability advocacy and awareness raising work in that country.

On completion of Stage 2, PDF in conjunction with its members will need to set its own priorities, but may choose to at least provide seed funds for local organisations to undertake similar disability awareness surveys as a way of gaining support as a disabled persons' organisation and conveying services directly to those in need. (And again, if required, *Inclusion International* or any of its more experienced Pacific partners could continue to be contracted to provide any technical or other assistance required.)

Recommendation 13: Over the next year or so regional disability funds should also be made available to enable the continuation and completion of national disability identification surveys, such as those initiated by *Inclusion International*, where requested by national coordinating groups or their equivalent.

Finally, many of those consulted during the preparation of this report were keen to see the results of their feedback. People are conscious that there is little research and analysis of disability issues in the Pacific, so what are available needs to be shared and made as available as much as possible for multiple uses. It was suggested by one of those consulted during this Review that “in the spirit of regional co-operation and collaboration this report be made publicly available soon for the benefit of regional and national work in the area”. It is likely that the material in this report will be of most relevance and use to people, the sooner it is released.

In particular, much of the report will be of direct relevance and interest to members of the Pacific Disability Forum. Due to communication difficulties and remoteness of many members, it may be most effective to mail printed copies to all PDF member organisations and PDF councillors, as well as making the Report available electronically.

Recommendation 14 This Report be distributed by NZAID to all who participated in the Review as soon as possible after it is accepted by NZAID.

Appendix I: Review Methodology

The Terms of Reference for the *Scoping Study and Review of NZAID Pacific Regional Disability Programme* are at Appendix VIII. As this outlines, the objectives for the Review were to:

1. “Review the *Inclusion International* Disabilities Project with a view to determining whether the project met its four objectives and completed the activities listed in the project document. In the context of 1 & 2, the Review should recommend whether extending this project should be a priority for NZAID funding as opposed to funding an indigenous provider (local regional agency) directly.
2. “Undertake a scoping study/environmental scan and provide a summary of key regional issues, donor involvement and activities in the area of disabilities. This summary should identify where there are significant or under-funded gaps. [This does not require original research. The information is available through the United Nations Economic and Social Commission for Asia and the Pacific (ESCAP), the Pacific Islands Forum Secretariat, Inclusion International and the Pacific Disabilities Forum.]
3. “Identify and evaluate the capacity and capability of key indigenous regional agencies (both government and non-government), in particular the Pacific Disabilities Forum.”

Orientation and Policy Context

The initial task was to identify, obtain and review relevant documents to establish familiarity with New Zealand’s approach to disability in the Pacific, how this relates to regional approaches, and to provide an orientation to the *Inclusion International* Pacific regional disabilities project in this context. This also required initial interviews with personnel from NZAID, *Inclusion International* and some other organisations.

The documents examined included:

- a review of relevant NZAID files, and substantial material including email exchanges provided by *Inclusion International* from its files⁴⁵;
- 20 *Inclusion International* reports on or for the Pacific Regional Disability Project;
- ten NZAID policy statements, handbooks and reports (including NZAID overall policy statement and various policy documents on education, health, human rights, and the Pacific);
- NZ Government’s *Disability Strategy* and progress reports;

⁴⁵ For the purposes of this Review, it was disappointing how incomplete various aspects of relevant NZAID files were found to be. We are extremely grateful for access provided by *Inclusion International* to its records and reports, which assisted in filling in many of these gaps.

- documents on the development of the draft *Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*;
- 27 reports from International Labour Organisation (ILO), Pacific Islands Forum Secretariat (PIFS); Secretariat for the Pacific Community (SPC), United Nations Economic and Social Commission for Asia & the Pacific (ESCAP), other United Nations agencies, and World Bank; and
- 12 reports from *Disabled People's International (Oceania)*, *Fiji Disabled People's Association (DPA)*, *Pacific Disability Forum (PDF)*, *Te Toa Matoa (Kiribati Association of People with Disabilities)*, *Vanuatu Disability Promotion & Advocacy Association (DPA)* and *Women with Disabilities Pasifika Network*.

In all, some 84 documents were reviewed during the course of the Review and these are listed at Appendix II.

Field Work: Interviews and Consultations

On the basis of this orientation and policy context, formats for interviews and workshops were developed to consult on these issues in five Pacific Island countries and in Aotearoa/New Zealand. Outlines of these formats are included at the end of this Appendix.

With the assistance of local contacts⁴⁶, ten consultation workshops were arranged. This included eight in-country workshops and two Pacific regional workshops:

- a general workshop with ten people with disabilities, a general workshop with 16 representatives of NGOs working with people with disabilities, a specialist workshop with 12 women & girls with disabilities⁴⁷, a specialist workshop with six people with intellectual disabilities or mental illness & two parents in Fiji;
- a general workshop with 12 people with disabilities, a specialist workshop for 6 women & girls with disabilities, and a specialist workshop with 5 people with intellectual disabilities in Tonga⁴⁸; and
- 19 people with disabilities and service providers in a combined workshop in Vanuatu (the conduct of this consultation along the lines of the standard workshop format was sub-contracted to *Vanuatu Disability Promotion and Advocacy Association*).

In association with a regional conference separately organised by the Pacific Islands Forum Secretariat in conjunction with PDF, a regional workshop for this Review was

⁴⁶ Local contacts who provided invaluable assistance to the Review in organising local workshops and interviews included: Sainimili Tawake in Fiji, Dimity Taylor and Margaret Verick in Tonga, and Andonia Piau-Lynch in Vanuatu. The Review could not have been undertaken without their assistance.

⁴⁷ Arrangements were made to ensure the workshops for women and girls with disabilities were facilitated (and where relevant translated) by women. In Fiji this was undertaken by Sainimili Tawake, and by Margaret Verick in Tonga.

⁴⁸ Translation assistance was provided by Rhema Misser and Lita Liutai in Tonga, and with signing by Tina Marell in Fiji.

also undertaken in Nadi, with 40 government and NGO representatives from 14 Pacific countries and various regional and international agencies (listed at Appendix VII); and a workshop was undertaken with eleven of the 12 PDF Executive members.

Also as a part of this field work, individual interviews were arranged with:

- five Inclusion International (past and current) officers and associates;
- ten NZAID and Ministry of Foreign Affairs & Trade staff in Wellington, Suva and Nuku'alofa;
- eleven heads or equivalent of government agencies in Cook Islands, Fiji and Tonga;
- 14 representatives of NGOs in Cook Islands, Fiji, Samoa, Tonga and Vanuatu⁴⁹
- ten representatives of Pacific regional NGOs; and
- seven representatives of Pacific regional agencies and global inter-governmental agencies operating in the Pacific⁵⁰.

Thus views were able to be canvassed from a wide range of Pacific countries (especially with 14 countries represented at the regional workshop), and in depth through the individual interviews and selected workshops. The consultation workshops did not provide a representative sample, so their views may not necessarily be generalised to all people with disabilities in the selected countries nor the Pacific⁵¹. Participants were selected by local contacts and, as such were more likely to be either receiving services from NGOs or in some contact with disabled person's organisations. The workshops operated in the same way as focus groups providing a range of views and understandings, and some insight in depth behind these views. Interviewees were selected (on the basis of advice from local informants) as representing the government agencies and NGOs with the most significant impact or involvement with disability issues in the selected countries. In addition, representatives from all key inter-governmental agencies involved in disability issues in the Pacific were interviewed. (Their interest or involvement in these issues was confirmed by their participation in the regional disability workshop in Nadi during the course of the Review.) Representatives of a number of regional NGOs were also interviewed, not just for their knowledge and involvement in disability issues (which with a few notable exceptions was generally limited), but also for insights into the practicalities of operating Pacific regional NGOs.

In all, some 57 individuals were interviewed and 120 took part in consultation workshops during the course of the Review (some individuals may be double counted

⁴⁹ In addition, 16 representatives of NGOs took part in a specific NGO workshop in Fiji, mentioned above, and five representatives of NGOs were included in the Vanuatu consultation workshop.

⁵⁰ In addition, government representatives from 13 Pacific countries and NGO representatives from 12 Pacific countries, along with 15 observers and resource people from inter-governmental organisations, national governments, and international and national NGOs took part in the Regional workshop, described above. Further details on the workshop are provided in Appendix VII.

⁵¹ Nevertheless, because of the process of canvassing multiple sources we have a good level of confidence in the validity of our findings. In particular, we found a strong similarity among the views expressed in different workshops, and between those of the workshop participant and key informants from government agencies and NGOs. We also found strong agreement on what were the key issues for people with disabilities in the Pacific between these views and what was identified in the document review.

where they were engaged in more than one consultation method). Organisational representatives interviewed are listed at Appendix III. The names of individual participants in the consultation workshops are not separately identified for privacy reasons.

Findings and Conclusions

The above field work and document review enabled the consultants to assess the impact of the four components of the *Inclusion International* Pacific Regional Disabilities Project⁵²; to identify the range of issues confronting people with disabilities in the Pacific, and to propose what the most strategic next steps might be to be supported by the NZAID Pacific Regional Disabilities Programme, including the appropriate auspice arrangements for such activities.

In assessing the impact of the *Inclusion International* project we considered the reports of what was undertaken and its impact, and sought the views of people with disabilities, those involved in implementing various aspects of the project, other NGOs and relevant government and intergovernmental agencies in the Pacific.

In identifying the range of critical issues for people with disabilities in the Pacific, we specifically sought views on what would be required to reduce inequalities between people with disabilities and others in the Pacific, what would empower people with disabilities in the Pacific, what was stopping these things from happening, what would most assist in addressing these barriers, and what (if anything) at a Pacific regional level could best support this activity.

In identifying the capacity of potential indigenous regional disability organisations, five assessment criteria were developed, and strengths and weakness of seven organisations were considered on each of these criteria. Assessment criteria were also developed in order to assess potential auspice arrangements.

Liaison and Reporting

During the course of the Review, draft records of interviews were provided back to interviewees for correction or clarification. All suggested changes or additions were incorporated. The process for the workshops involved writing up comments and conclusions of the group on flip chart paper, so that any misunderstandings or disagreements could be dealt with on the spot. Copies of the write-up of this workshop material was also provided back to local organisers of the workshop groups to provide participants with a written record, if requested. This helped to ensure that any bias in interpretation from the consultants was minimised.

In addition, after the completion of most of the field work, a briefing was arranged with key NZAID staff to make them aware of emerging issues, and the likely direction of this final report. Feedback was especially sought on any additional areas on which NZAID would require information or advice in order to make best use of the Review. This did not affect the content of advice or information provided, but

⁵² The four components of the *Inclusion International* Pacific Regional Disability Project were: establishment of Pacific Disability Information Network (PDF Listserv); review of all disability related legislation in the Pacific; undertaking disability identification surveys in a number of Pacific countries; and arranging a regional 'Disability in the Pacific Study' meeting.

helped to ensure that the report covered all the areas necessary for NZAID to make its decisions in this area.

Copies of relevant sections of the draft report were provided to *Inclusion International*, NZAID, the consultants' in-country contacts, and to the PDF executive. This was both to again ensure a final quality check and accuracy of all factual material, and to obtain feedback and reaction on the reasonableness of our findings and the workability of our proposals. This indeed provided much valuable feedback, and a number of changes and additions were made to the final report as a result.

Attachment A: Format for Consultation Workshops

The following briefing material on the workshops was provided to local contacts involved in organising the Consultation Workshops and describes the format broadly followed by the consultants. Specific questions were adapted for particular groups.

Time: Approx 2 1/2 hours including break. Times given below are indicative. The break could be morning/afternoon tea or lunch.

Venue: A fully accessible venue large enough for about 20 participants to sit with plenty of space for entry and exit by people with a range of disabilities.

Numbers: Expecting at least 10-15 people but more would be welcome (depending on venue).

Purposes of Workshop:

1. Understand the potential of in-country activity to promote equality (between people with disabilities and others) and promote the empowerment of people with disabilities.
2. Consider any recent successes in promoting equality and empowerment for people with disabilities.
3. Explore the implications for regional activity.

Target Audience: People with disabilities, their families, carers and other unpaid supporters are the people whom we seek to attract to this workshop. It is hoped that a variety of disabilities will be represented, males and females and a spread of ages if at all possible.

In recognition of the difficulties faced by some of these groups in speaking comfortably in an open forum a couple of targeted smaller forums can be held for some groups (eg women and girls with disabilities, and people with intellectual disabilities).

Context: The workshop is part of a review being conducted for New Zealand Agency for International Development (NZAID) on its Pacific regional disability program. So far NZAID's program has primarily supported the work of Inclusion International in the region with a 3-year project to:

- a. *Establish a Pacific Disability Information Network to share information and to provide support for people with disabilities in Pacific countries;*
- b. *Undertake a review of all disability related legislation in Pacific countries in order to assist each country to meet key targets outlined in the UN Agenda for Action for the Asian and Pacific decade of Disabled Persons;*

- c. *Undertake a needs analysis of people with disabilities in a number of Pacific Countries in order to put in place mechanisms for further support for individuals with disabilities; and*
- d. *Coordinate a further “Disability in the Pacific Study Meeting” to bring together representatives from those countries where the Disability Identification Survey is being used to benefit people with disabilities and their families.*

The focus of the Review is not just on the extent to which this project achieved its objectives, but also especially about what the future priorities and focus should be for NZAID’s Pacific Regional Disability programme.

SUGGESTED WORKSHOP OUTLINE

9.30 Open and introductions

Short (optional) ice breaker depending on how comfortable the group members are with each other. For example, either:

- each person giving his/her name and the origins of that name; or
- groups of three quickly discussing their opinions of the greatest challenge(s) for people with disabilities in [country].

9.45 Background

Introduce and describe the theory of change chain and the NZAID dual track approach. The two tracks cover :

- addressing inequalities between people with disabilities and others; and
- what specifically empowers people with disabilities?

10.00 What could make the difference?

Overall for people with disabilities

1. What could be the most important things to reduce inequalities for people with disabilities in [country]?
2. What could be the most important things to specifically empower people with disabilities so that they have more control over their lives and achieve what they want?
3. What could stop or get in the way of this happening in [country]?

For Organizations of people with disabilities

4. What could organizations like [country disabled persons’ organization] best do to:
 - help reduce inequalities for people with disabilities and
 - help empower people with disabilities?
5. What makes it harder for organizations like [country disabled persons’ organization] to do this work?
6. What would best assist organizations like [country disabled persons’ organization] to help reduce inequalities and empower people with disabilities?

At a regional level in the Pacific

7. What Pacific regional support and/or networks could best help organizations like [country disabled persons’ organization] to do this work?
8. What (if anything) regionally could get in the way of the work of organizations like [country disabled persons’ organization]?

11.00 Break for refreshments

11.30 What's been happening?

What has been happening in [country] that has helped to date to achieve (a) equality and (b) empowerment for people with disabilities?

(Use the above questions 2-8 (in past tense) if necessary as prompts to explore recent developments.) What can we learn from this? (if not already apparent)

12.00 Wrap up

Thanks to all participants. Reiteration of what their input will be used for. Advise that the notes of the workshop will be emailed to whom ever the group nominates.

Attachment B: Standard Format for Interview Questions

The following issues were addressed in interviews with national NGOs and representatives of Pacific government agencies:

1. What has been done in [country] recently to promote equality and empowerment for people with disabilities?
2. How successful has it been?
3. In particular has the work done by Inclusion International in [country] been useful?
4. What use, if any, has been made of data collection from the Inclusion project or by government?
5. What is required to promote equality and empowerment for people with disabilities in [country] in the future?
6. What might [country disabled persons' organization] do to promote equality and empowerment for people with disabilities in [country]?
7. What could be done at a regional level to assist [country disabled persons' organization] in this work?

The following issues were addressed in interviews with Pacific regional NGOs and inter-governmental agencies:

1. What has been done in the Pacific recently to promote equality and empowerment for people with disabilities?
2. How successful has it been?
3. In particular has the work done by Inclusion International in the Pacific been useful?
4. What use, if any, has been made of data collection from the Inclusion project?
5. What is required to promote equality and empowerment for people with disabilities across the Pacific in the future?

6. What might local organisations of disabled people do to promote equality and empowerment for people with disabilities in-country?
7. What could be done at a regional level to assist disabled persons' organisations in their in-country work?
8. What are the opportunities and challenges for such a regional organisation of and for disabled people, including
 - Governance;
 - Management;
 - Financial/resource implications; and
 - Other capacity issues for a consumer based organisation?

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Appendix III: People and Organisations Consulted

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Aotearoa/New Zealand

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Helen Tavola, *Social Policy Advisor, Development and Economic Policy Division, Pacific Islands Forum Secretariat (PIFS)*

AM Zakaria, *Director, Office for the South Pacific, International Labour Organization (ILO)*

Specialist Workshop with six people with intellectual disabilities and mental illness and two parents, Suva

Specialist Workshop with twelve women and girls with disabilities, Suva

General Workshop with ten people with disabilities, Suva

General Workshops with sixteen representatives of NGOs working with people with disabilities, Suva. Organisations represented included: *Counterstroke Fiji*, *Fiji Association of the Deaf*, *Fiji Disabled Persons Association (FDPA)*, *Fiji National Council for Disabled Persons (FNCDP)*, *Fiji Vocational Training and Technical Centre (FVTTC)*, *Gospel School for the Deaf*, *Suva Special School*, *Psychiatric Survivors Association (PSA)*, *Spinal Injury Association (PIA)*, *Suva Society for Intellectually Handicapped Children*, and *United Blind Persons*.

Workshop with five of the six Pacific Disability Forum Executive Committee members, Nadi

Workshop with 40 government and NGO representatives from 14 countries and various regional and international bodies, Nadi (listed at Appendix VII)

New Caledonia

Scott Pontifex, *Geographical Information System Programmer, Demography and Population Programme, Secretariat of the Pacific Community (SPC)*

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Michael McBryde, *High Commissioner, New Zealand High Commission*

Hon Prince Mailefihi, *Tonga National Paralympics Committee & Tonga Amateur Sports Association and National Olympics Committee (TASANOC)*

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Keasi Pongi, *Development Programme, New Zealand High Commission*

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Viliama Takau, *Director of Education, Ministry of Education*

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Specialist Workshop with five people with intellectual disabilities, Nuku'alofa

Specialist Workshop with six women and girls with disabilities, Nuku'alofa

General Workshop with twelve people with disabilities, Nuku'alofa

Vanuatu

Andonia Piau-Lynch, *Coordinator, Vanuatu Disability Promotion and Advocacy Association (DPA)*

Alistair Wilkinson, *Regional Advisor, Social Development and Planning, United Nations Economic and Social Commission for Asia and the Pacific, Pacific Operations Centre (UNESCAP-POC)*

General Workshop of 21 people with disabilities and service providers, Port Villa (and two observers from People with Disability Australia). Organisations represented included: *Department of Health, EDA Motalava, Frangipani Association, Pacific Skills Link, vandisports, Vanmolmol Association, Vanuatu Disability Promotion and Advocacy Association (DPA), Vanuatu Family Health Association, and Vanuatu Society for Disabled People (VSDP).*

Appendix IV: Overview of Biwako Millennium Framework

Lake “Biwa” is the largest freshwater lake in Japan, in the City of Otsu. It is in this city that the High-level Intergovernmental Meeting to Conclude the Asian and Pacific Decade of Disabled Persons was held. Hence, the name of the framework is “Biwako” (“ko” means a lake). The word “Millennium” indicates that the Framework was adopted at the beginning of the new millennium and also that it is structured to supplement the United Nations Millennium Development Goals and targets. “An Inclusive, Barrier-free and Rights-based Society” represents the guiding principles of this framework. An “inclusive” society is a society for all, and a “barrier-free” society refers to a society free from institutional, physical and attitudinal barriers, as well as social, economic and cultural barriers. A “rights-based” society means a society based on the human rights of all individuals where peoples with disabilities are valued and placed at the centre of all decisions affecting them.⁵³]

Biwako Millennium Framework for Action: Towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific

In May 2002, in Biwako Japan, ESCAP adopted the resolution “Promoting an inclusive, barrier-free and rights-based society for people with disabilities in the Asian and Pacific region in the twenty-first century”. The resolution also proclaimed the extension of the Asian and Pacific Decade of Disabled Persons, 1993-2002, for another decade, 2003-2012.

In October 2002, Governments at the High-level Intergovernmental Meeting to Conclude the Asian and Pacific Decade of Disabled Persons 1993-2002, adopted the “Biwako Millennium Framework for Action towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asian and the Pacific”, as the regional policy guideline for the new decade.

The “Biwako Millennium Framework” outlines issues, action plans and strategies towards an inclusive, barrier-free and rights-based society for persons with disabilities.

To achieve the goal, the framework identifies seven priority areas for action, in each of which critical issues, targets with specific timeframes, and actions are specified. In all, 21 targets and 17 strategies supporting the achievement of all the targets are identified.

The new decade (2003-2012) has the potential to ensure the paradigm shift from a charity-based approach to a rights-based approach to protect the civil, cultural, economic, political, and social rights of persons with disabilities.

To pursue the targets and strategies, consultations with and involvement of civil society, inter alia, self-help organizations and concerned NGOs are essential.

⁵³ This Appendix is based on “Annex: Biwako Millennium Framework” in UNESCAP (2003) *Focus on Ability, Celebrate Diversity: Highlights of the Asia Pacific Decade of Disabled Persons, 1993-2002*, (Social Policy Paper No. 13) [ST/ESCAP/2291], United Nations, New York

The following sections summarize the seven priority areas for action, the targets, strategies, time-frames, and the supporting/monitoring mechanisms.

A. Self-help organizations of persons with disabilities and related family and parent associations

Persons with disabilities and their self-help organizations are the most equipped and best informed to speak on their behalf and can contribute to solutions on issues that concern them. Two targets are set to make the difference:

(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.

Self-help organizations should include marginalized persons with disabilities such as women and girls with disabilities, persons with intellectual disabilities and persons with psychiatric disabilities.

B. Women with disabilities

Women with disabilities are multiply disadvantaged through their status as women, as persons with disabilities, and their likelihood to be living in poverty. Three targets are set to solve these problems:

(1) By 2005, Governments should ensure anti-discrimination measures, where appropriate, to protect women with disabilities.

(2) By 2005, self-help organizations should adopt policies to promote full representation of women with disabilities.

(3) By 2005, women with disabilities should be included in the membership of national mainstream women's associations.

C. Early detection, early intervention and education

Fewer than 10 per cent of children and youth with disabilities 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 Asian and Pacific region. This exclusion from education for children and youth with disabilities results in exclusion from opportunity for further personal, social and vocational development. Four targets are set for these problems:

(1) 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.

(2) 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.

(3) By 2012, all infants and young children (0-4 years) will have access to and receive community-based early intervention services.

(4) Governments should ensure detection of childhood disabilities at a very early age.

Actions in this area include adequate legislation for inclusive education and national data collection on children with disabilities (0-16 years).

D. Training and employment, including self employment

Persons with disabilities remain disproportionately undereducated, untrained, unemployed, underemployed and poor. They have insufficient access to the mainstream labour market partially due to social exclusion, lack of trained and competent staff and adequate training for independent workers. Three targets follow:

(1) By 2012, at least 30 per cent of the signatories (member states) will ratify ILO Convention 159 concerning Vocational Rehabilitation and Employment (Disabled Persons).

(2) By 2012, at least 30 per cent of all vocational training programmes in signatory countries will include persons with disabilities.

(3) By 2010, reliable data on the employment and self-employment rates of persons with disabilities will exist in all countries.

E. Access to built environment and public transport

Inaccessibility to the built environment, including public transport systems, is still the major barrier for persons with disabilities. This problem will only be exacerbated, as the number of older people with disabilities increases in the region. Universal design approaches benefit all people in society, including older persons, pregnant women and parents with young children. Its economic benefits have been legitimized, yet substantive initiatives at policy level have not been taken. Three targets are set to improve the situation:

(1) Governments should adopt and enforce accessibility standards for planning of public facilities, infrastructure and transport, including those in rural/agricultural contexts.

(2) Existing public transport systems and all new and renovated public transport systems should be made accessible as soon as practicable.

(3) All international and regional funding agencies for infrastructure development should include universal and inclusive design concepts in their loan/grant award criteria.

F. Access to information and communications, including information, communication and assistive technologies

In the past 10 years, there has been much progress in information and communication technology (ICT) development, and it opens up many opportunities for people with disabilities in networking, solidarity, employment and independent living. But it has also widened the gap between persons with disabilities and the non-disabled. The digital divide includes inaccessibility to infrastructure for ICT, Internet, and ICT skills. These problems are acute in rural areas. The multimedia environment is

creating barriers for people with visual disabilities. Five targets are set to improve the situation:

- (1) 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.
- (2) By 2004, international organizations should incorporate accessibility standards for persons with disabilities in their international ICT standards.
- (3) Governments should adopt, by 2005, ICT accessibility guidelines for persons with disabilities in their national ICT policies.
- (4) Governments should develop and coordinate a standardized sign language, finger Braille (tactile sign language), in each country and disseminate and teach the results through all means, i.e. publications, CD-ROMs, etc.
- (5) 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 productive employment.

G. Poverty alleviation through social security and livelihood programmes

Persons with disabilities are the poorest of the poor. It is estimated that 160 million persons with disabilities (over 40 per cent of the total) are living in poverty, unable to benefit from their socio-economic rights. Poverty and disability are mutually reinforcing as persons with disabilities are socially excluded and adequate social services are not provided. Pursuant to the United Nations Millennium Development Goal target 1:

- (1) 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.

National plan of action (five-year) on disability

Strategy 1 calls for Governments to develop and adopt, by 2004, a five-year comprehensive national plan of action to implement the targets and strategies of the framework.

Promotion of rights-based approach to disability issues

Strategy 2 calls for Governments to examine the adoption and implementation non-discrimination policies. Strategy 3 draws attention to National Human Rights Institutions as agencies to protect disabled people's rights. Strategy 4 calls for Governments to actively involve persons with disabilities in any policy development. Strategy 5 calls for Governments to consider ratifying the core international human rights treaties. Strategy 6 calls for Governments to consider support for the Ad Hoc Committee for the comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities. Strategy 7 calls on Governments to include persons with disabilities and their organizations, in their procedures at the national, regional and international levels, concerning the drafting and adoption of the proposed human rights convention on disability.

Disability statistics/common definition of disabilities for planning

A common system of definition and classification of disability is not uniformly applied in the region. Two strategies are set to solve the problem. Strategy 8 calls for Governments to develop, by 2005, their system in disability-related data collection and analysis. Strategy 9 calls for Governments to adopt, by 2005, definitions on disability based on the United Nations publication "Guidelines and Principles for the Development of Disability Statistics.

Strengthened community development approach to prevention, rehabilitation and empowerment of persons with disabilities

The community-based approach is augmenting and replacing traditional institutional and centralized rehabilitation programmes for disabled people's economic, social and other human rights enhancement. Strategy 10 calls for Governments to immediately develop national policies to promote community-based approaches.

Cooperation and support for action: sub-regional, regional and interregional

A special focus is on strengthening cooperation among governments at the sub-regional level. Strategies 11 and 12 call for developing sub-regional mechanisms, by 2004, to achieve the targets. At a regional level, strategy 13 calls for Governments, the United Nations system, civil society organizations and the private sector to collaborate, support and take advantage of the training and communication capability of the Asia-Pacific Development Center on Disability. This centre is to be opened in 2004 in Bangkok, as a legacy of the Asian and Pacific Decade of Disabled Persons. It has the capacity to be one of the most powerful focal points in the region. Strategies 14 and 15 call for Governments, civil society organizations and the private sector to establish a network of centres of excellence in focused areas to maximize cooperation and collaboration. ESCAP and other United Nations agencies should assist in the establishment of a network of centres of excellence. Strategy 16 calls for a suitable agreement on trade, technology transfer and human resource development for fast and efficient sharing of resources. Strategy 17 proposes that the Asian and Pacific region, the African region and the Western Asian region should strengthen their cooperation and collaboration to create synergy in implementing regional decades through interregional exchange of information, experiences and expertise, which will mutually benefit all the regions.

Monitoring and review

ESCAP should convene biennial meetings to review achievements and to identify actions that may be required to implement the Biwako Millennium Framework for Action. At these meetings, the representatives of national coordination committees on disability matters comprising Government ministries/agencies, NGOs, self-help organizations and the media will be invited to present reports to review progress in the implementation of the framework.

A mid-point review of the Biwako Millennium Framework for Action should be conducted. Based on the review, the targets and strategic plans for the second half of the Decade may be modified and new targets and strategic plans formulated.

Appendix V: Disability Questions and Data in Pacific Island Country Censuses

This appendix provides an overview of disability related questions in those Pacific Island country censuses which have recently included such questions. Where data is available, an indication of the relevant compiled data is then given. Twelve Pacific Island countries have generated census data on disabilities, but definitional problems make it difficult to compare data.

American Samoa

2000 Census of Population and housing.

Disability status of the civilian non-institutionalised population:

	<i>Number</i>	<i>Percent</i>
Population 21 to 64 years	26,921	100.0
With a disability	6,119	22.7
Percent employed	58.8	Not applicable
No disability	20,802	77.3
Percent employed	57.8	Not applicable

Cook Islands

Census 1996

Activity Status: Tick circle which applies

Activity Status no10 – Disabled, If ticking disabled instructed to go onto question 17

Question 17- Unpaid work: Tick as many circles as you may require.

Fiji Islands

Census 1996

C1. Does any person in this household have any disability or health problem that is long term? (Lasting 6 months or more).

C2. Does this person as a result of this condition have difficulty with or cannot do?
Tick appropriate box

Everyday activities that people his/her age can do
Communicating, mixing with others or socializing
Any other activity that people his/her age usually do
OR

No difficulty with any of these

C3. What is the nature of the disability?

Insert code in appropriate box.

- | | |
|-----------------|------------|
| 1. sight | 4.physical |
| 2. intelligence | 5.age |
| 3. hearing | 6.other |

Guam

2000 Census of Population and housing

Disability status of the civilian non-institutionalised population

	<i>Number</i>	<i>Percent</i>
Population 21 to 64 years	79,930	100.0
With a disability	17,405	21.8
Percent employed	62.7	Not applicable
No disability	62,525	78.2
Percent employed	65.9	Not applicable

Kiribati

Census 2000

Information which links to disability in the Kiribati census:

Disabled: If the person was seriously disabled that he/she did no work of any kind, write 'Disabled'. Included also are people who have been sick for quite a long time.

If the person did no work last week but is in none of the categories mentioned above, write a one or two words explanation- for example 'mental', 'patient', or 'prisoner'.

Marshall Islands

Census 1999

Disability

Does ___ have any physical or mental disability?

What type of disability does ___ have?

(A list of the types of disability the person may have is provided.)

Reason for not looking for work

Why did ___ not look for work ?

One of the answers to choose from is:

6. Too young, too old or retired.

Permanent disability

Sources of income

What are the sources of income of this household?

Answer E. Social security, retirement, survivor and disability pensions.

Table 14. Population with Disability by type of Disability, Age group and sex, Republic of the Marshall Islands: 1999

The total number of people with a disability (both sexes) is 853.

The number of Males with a disability is 496, The highest type of disability for Males being Blindness is 87.

The number of Females with a disability is 357, The highest type of disability for Females being Deafness is 64.

Micronesia

Census 2000

Question 32d: How much did ___ receive in social security payments or any pension payments from retirement, survivor, or disability?

Nauru

Census 2002

Question 40: What is the main reason why (name) did not work last week?

One of the answers is :

05. Disabled

Commonwealth of the Northern Mariana Islands

2000 Census of Population and housing

Disability Status of the civilian non-institutionalised population

	<i>Number</i>	<i>Percent</i>
Population 21 to 64 years	47,315	100.0
With a disability	7,696	16.3
Percent employed	79.0	Not applicable
No disability	39,619	83.7
Percent employed	86.6	Not applicable

Niue

2001 Census of Population and housing

Question 16: Main Activity during a week prior to census

This question applies to persons 15 years and above. It is asked to obtain employed and unemployed persons, economically active and economically not active persons. The categories of main activities were as follows:...

One category was: Other (pensioner, disabled etc.)

Papua New Guinea

Census 2000

What was the person doing mostly in the last 7 days?

One of the answers was:

8. Permanently Disabled

Samoa

Census 2001

P13. Please indicate if this person is disabled or not. 1. Disabled 2. Not disabled

Table 11. Population with Disability by 5 Year Age Group and Gender, 2001

Total number of Males with a Disability: 1,279	
Total number of Females with a Disability: 1,016	Total: 2,295
Total number of Males with no Disability: 90,850	
Total number of Females with no Disability: 83,701	Total: 174,551

Table 14. Disabled by 5 Year Age Group, Main Activity and Gender, 2001

Total number of Males Main Activity as Paid Work: 101	
Total number of Females Main Activity as Paid Work: 53	Total: 154
Total number of Males Main Activity as Earning Money: 8	
Total number of Females Main Activity as Earning Money: 2	Total: 10

Table 18. Population without Disability 5 to 29 Years of Age by School Attendance and Gender, 2001

Total number of Males Attending School full time: 28,637	
Total number of Females Attending School full time: 26,603	Total: 55,240
Total number of Males not Attending School: 18,434	
Total number of Females not Attending School: 15,692	Total: 34,126

Table 19. Population with Disability 5 to 29 Years of Age by School Attendance and Gender, 2001

Total number of Males Attending School full time: 294	
Total number of Females Attending School full time: 228	Total: 522
Total number of Males not Attending school: 341	
Total number of Females not Attending school: 280	Total: 621

Solomon Islands

1999 Census

Private households, by presence of disabled members and size of household and by province, also by urban-rural distribution

<i>Province also Urban rural distribution</i>	<i>Total number of households with Disabled members</i>	<i>Total number of households not fully stated</i>
Solomon Islands	8,824	726
Choiseul province	445	32
Western province	1,361	119
Isabel province	398	34
Central province	455	24
Rennell-Bellona province	108	10
Guadalcanal province	1,284	93

Malaita province	2,844	246
Makira-Ulawa province	663	92
Temotu province	543	29
Honiara town council	723	47
Urban	855	80
Rural	7,969	646

P8. Disability

Do you have any problem seeing, hearing, talking, moving, holding, gripping or any mental problem?

P25. Why not worked for pay

What is the reason that you did not work for money or payment in kind in the last 7 days?

list of answers given, one of which is 'Disabled'

7.2 Disabilities

The 1999 Census question on Disability screens the population by self-perceived status of health in terms of functioning and Disability.....

The question in the 1999 Solomon Islands census is meant to screen the population at large, not to describe in detail individual health conditions in terms of the ICDH-2'.

Figure 7.2. Percentage distribution of Disabled persons, by type of Disability

<i>Disability</i>	<i>Percentage</i>
Seeing	32%
Hearing	18%
Moving	17%
Speaking	7%
Mental	6%
Gripping	4%
Multiple	16%

Types of Disability are categorized. Some information is provided on each.

7.2.3.1 Blindness and visual disabilities

7.2.3.2 Deafness and hearing impairment

7.2.3.3 Speaking disability

7.2.3.4 Moving and gripping

7.2.3.5 Mental Health

7.2.3.6 Multiple disabilities

Table 7.4.

Number and percentage of disabled persons aged 14-64 Years, by Economic activity status in Paid or Unpaid work and by Sex

Tokelau

Census 2001

Question 27. If ___ had a job, could he or she have started work this week?

Lists a number of answers one of which is:

4. No, Disabled

Tonga

Census 1996

Question 16. Economic Activity Last week (Ask only those 15 and over)

Did this person work at any time in the reference week, either full time or part time?
(work includes helping without pay in a family business, and with farming/gardening/fishing/handicrafts)

Under the second choice of 'NO'

Reason No6 is 'Disabled/Handicapped'

Table G16. Tongan (including part-Tongan) not economically active population aged 15 years and above by division, Nuku'alofa, by sex by age group by main activity

	<i>Disabled</i>
Nuku'alofa	
Male and Female Total	101
Male Total	54
Female Total	47
Greater Nuku'alofa	
Male and Female Total	147
Male Total	76
Female Total	71

Tuvalu

Census 2002

P27. If ___ found a job, could he or she have started work last week? (Circle one answer code)

One of the answers is:

4. No, Disabled/ retired

Table 8. Activity status, by sex and Island religion

(Non Labour force/ Not economically active)

<i>Island/ Religion</i>	<i>Retired/ Disabled</i>
Males	
Funafuti	20
Outer Islands	37
Tuvalu	57
Females	
Funafuti	22
Outer Islands	46
Tuvalu	68

Total	
Funfuti	42
Outer Islands	83
Tuvalu	125

Vanuatu

1999 Census

P21A. What is the main reason that you do not work?

One of the answers is:

3. Disabled

Acknowledgement:

This Appendix is based on census questionnaires and census data analysis reports were made available by the Demography Programme of the Secretariat of the Pacific Community (SPC).

Appendix VI: Examples of Impacts of Data Collection

The following specific development impacts are based on those identified in an interim report on the Inclusion International Project in 2004. They have been updated by this Review to include impacts identified since that time.

Cook Islands

“Since the virtual completion of the survey, the Cook Islands Government has been taking a greater interest in disability issues and NZAID has been increasing its support.” There is now a Disability Action Team in place (2 locals and a NZ Consultant with the key objectives to facilitate implementation of the National Disability Policy and Strategy (via Communication, capacity building, training and development and advocacy.

Development Impacts:

- “Development of a National Policy on Disability.
- “Special Education Adviser to further develop the Special Education Policy, which has strengthened the understanding and acceptance of children with disabilities into mainstream schools. This is resulting in an increase in the numbers of children with disabilities attending schools.
- “The Adult Creative Centre continues to provide arts, crafts and living skills opportunities for adults
- “The NZ Governor General on her recent sea voyage delivered equipment and appliances collected in NZ to Rarotonga
- “Advocacy work of Cook Islands Disability Council regarding disability issues such as access (new Supreme Court building design) and human rights.”

Fiji

A survey along the same lines as other countries was proposed to a group representative of the disability sector in 2002. this methodology was not taken up, instead a different data collection approach has been pursued.

“The Fiji National Council for Disabled Persons has developed a proposal currently being considered by the Fiji Government for a pilot survey in a designated area... which would then lead to a comprehensive country-wide survey to identify all people with disabilities in Fiji.” (No further developments to date.)

Kiribati

“..The National Disability Survey Advisory Committee has met regularly and developed its survey plan, finalized the questionnaire, secured funding and appointed a survey coordinator. ...Training of potential surveyors has continued and a pilot survey undertaken...” the survey was completed and the report was launched at the Kiribati parliament in May 2005.)

Development Impacts:

- “Capacity building of the survey committee through developing strategic plans for implementation of the survey, learning how to apply for funds from

various donors, setting, reviewing and monitoring the budget and hiring and monitoring the activities of the survey coordinator.

- “A group of surveyors from the South Tarawa survey were selected to undergo further training (conducted by Inclusion International but with the content developed with local stakeholders) to enable the outer island process. This training included being able to run community/village disability awareness workshops, recruiting and training local people to assist with the survey process and overseeing the survey implementation... The skills and capacities of this group continue to develop and they are seen as good role models as well as skilled facilitators and educators.
- “For many people with disabilities, the South Tarawa survey has already begun to identify unmet needs, some of which are now being addressed by the Physiotherapy Department and others.
- “Te Toa Matoi, the organization of disabled persons which] is the host society for the survey... continue to develop their skills by participating as both trainers and surveyors. They are developing a new strategic plan that will provide more coordination of their many activities with an aim towards developing a plan for sustainability. They are developing (and have run some trial) Women with Disability Life Skill courses – [involving] literacy, craft, personal skills, etc. They are increasing the visibility and positive activities of people with disabilities through their dramas, music (one CD is about to be released), and the opening of their new maneaba by the President of Kiribati. The maneaba opening has resulted in one of their members being offered a part-time position at the British High Commission.”
- Since the survey report there has been a 2-day workshop with all key stakeholders to identify priorities and a process for action. The local people secured sufficient local funding for a further workshop to finalise the outcomes of the September workshop which will be held later in 2005.
- Te Toa Matoi completed their second IHC/VASS funded project including the Band of the Blind Boys of Kiribati, undertaken a new drama presentation and had it recorded on DVD and have an active Women with Disability group.
- Inclusion International and Volunteer Service Abroad (VSA) are collaborating together with the local school for the disabled parent support group for the appointment of a... school coordinator.”
- VSA have returned to Kiribati with two teachers to work in the School for the Disabled.

Samoa

“The survey committee completed initial identification of people with disabilities living in Samoa, with great cooperation from the Department of Statistics, Nuanua o le Alofa (NOLA, a disabled persons’ organization) and many others.”

Development Impacts:

- “The survey committee is now known as the Disability Task Force and is working closely with the various Ministries in Samoa, including the Office of the Prime Minister, where a desk on disability issues is about to be established. A good rapport has been established with the NZ High Commission, UN agencies and kindred organizations.

- “Family empowerment workshops have been conducted and parent support groups have been started.
- “Close partnership with NOLA continues to develop strategies to implement the survey report recommendations.
- “Publications such as a Parents Kit and a brochure on epilepsy, plus a booklet on statistics relating to women with disabilities, have been widely distributed.
- “...Significant public awareness and participation has been developed in response to meeting some of the identified unmet needs of children and adults with disabilities and their families.
- “A number of people with disabilities are now gainfully employed as a direct result of the survey and others are involved in participating in income generating schemes with Women in Business.
- “More children with disabilities are attending school and more teachers are being trained to support children with disabilities at their village schools.
- “NOLA now has an office and employs several people with disabilities. They are supporting a self-advocacy group for people with an intellectual disability.
- “Samoan Inclusion International in-country representatives are facilitating the survey process in Tonga, therefore beginning the development of promoting and using Pacific regional expertise.”
- An Early Intervention Service has been established and continues to operate.
- The National University of Samoa has introduced a compulsory Inclusive Education paper for all teacher trainees.
- Parent support groups have been established and are running. Nofo Mapusa (a person with a disability) has had his term continued as Chair of the Disability Action Group.

Solomon Islands

“In May 2004 the Disability Survey Advisory Committee was re-established and is now actively progressing the survey process.” (It is now expected to be finished in 2005.)

Development Impacts:

- “Capacity building of the Survey Advisory Group through development of timeframe, budget and organizational plans for implementation of the survey.
- “Increased involvement of government and donors through networking and relationships being developed through the Disability Advisory Committee.
- Pilot survey completed in Honiara and Central Province with the national survey underway in 2005.
- Teacher training is now including Special Needs Education.

Tonga

“The Samoan in-country representatives are facilitating this process with supervision from the [Inclusion International] project coordinator.” (The pilot on ‘Eua has now been completed, additional funding attracted and now being rolled out on an island by island basis.)

Development Impacts:

- “Establishment of DAction (Disability Action Committee) to promote and progress the survey in Tonga [and provide a coordinated approach to disability

issues by all people and organisations currently involved, especially service providers].

- “Establishment of Nua Nauau ‘o e ‘Alamaite Association (NATA) – this [disabled persons organization] has written their constitution and are in the process of registering as an NGO [Since then they have registered as an NGO in November 2004 and are now in the process of trying to find office space and become registered with DPI and PDF]
- [Capacity building and education of NATA members and DAction members]
- [Networking and ownership of results through NGOs and government agencies, especially the Ministry of Education]
- “Disability Sport programme established in connection with Tonga Amateur Sports and National Olympic Committee (TASANOC). Two sports days have been held and students with disabilities have been included in the regular school sports competitions for the first time.”
- Pilot survey completed and now seeking funding for nationwide survey started.
- [People provided with equipment such as wheelchairs in areas surveyed]
- [Children in a Ha’apai school with visual impairment directed to services through contact with survey team]
- [Plans for a hearing and vision screening to be compared with survey results relating to children with perceived ‘learning disabilities’]
- [Awareness by service providers that current service provision is not sufficient and must be extended in some way. Already some extension of service to newly identified people.]
- [Many community members educated through field work]

Tuvalu and Tokelau

“No visits planned but phone links and emails with local societies, individual advocates and families will continue.”

Vanuatu

“Pilot survey was undertaken on Tanna Island... and is to be completed later this year (2004) and expanded to other provinces in 2005. Since that report the pilot covering all of Tafea province has been completed and have sought funding for a nation wide survey.

Development Impacts:

- “Increase in survey skills and organisational skills provided through training and implementation of the Tanna pilot survey.
- “...Initial findings presented to a wide range of government NGO, donor and disability organisations resulting in raised awareness, offers of assistance and increased understanding of some disability issues.
- “Development of a Special Education policy by newly appointed Special Education Adviser who will work cooperatively on the survey as well.
- “Capacity building of Vanuatu Society for Disabled People through participatory training workshop with Inclusion International resulting in the development of a fieldworkers’ Manual.”

General

“A significant amount of equipment has been donated and shipped to various countries as follows: 38 wheelchairs, 17 specialised buggies, 22 walking frames, 35 white canes, 20+ pairs of crutches, 30 pairs of reading glasses, 20 talking watches/clocks, and a wide range of school equipment.”



PACIFIC ISLANDS FORUM SECRETARIAT

PIFS/ILO/UN-EPOC/DPI/PDF

Appendix VII: Pacific Regional Workshop on Disability,

Tanoa International Hotel Nadi, Fiji (1-4 August 2005)

1. Representatives from governments of Australia, Cook Islands, Federated States of Micronesia, Fiji, Kiribati, Nauru, New Zealand, Niue, Palau, Papua New Guinea, Solomon Islands, Tuvalu and Vanuatu; along with representatives from non-governmental organisations from Australia, Cook Islands, Fiji, Kiribati, New Zealand, Palau, Papua New Guinea, Samoa, Solomon Islands, Tonga, Tuvalu and Vanuatu, met in Nadi from 1-4 August 2005. Observers from the University of the South Pacific, UNESCO, the European Commission, UNDP-Regional Rights Resource Team, Fiji Human Rights Commission, Asia Pacific Centre on Disability (APCD), Inclusion International and Rehabilitation International also attended the workshop.
2. Resource people were from Pacific Disability Forum (PDF), UNESCAP/POC, International Labour Office (ILO), Pacific Islands Forum Secretariat, Vision Pacific Charitable Trust (New Zealand), Fiji National Council for Disabled Persons, Fiji Employers Federation and Fiji Public Service Association, Donna Lene (Samoa), Mrs Maresilina Tabalailai, Fiji Ministry of Education.
3. Participants expressed their appreciation for the convening of this Pacific regional workshop on disability as it was the first workshop that brought this range of partners together. Sincere thanks were conveyed to the New Zealand Agency for International Development (NZAID) for funding the workshop and the ILO for funding support provided through Development Cooperation, Ireland.
4. The workshop was opened by a Deputy Secretary General of the Forum Secretariat, Mr Iosefa Maiava. He noted that the disability community has used the Forum processes very effectively, resulting in a discussion of disability at the 2003 Pacific Islands Forum reflected in the Communiqué, which endorsed the Biwako Millennium Framework and provided a mandate for regional work on disability.
5. Remarks were also made by the International Labour Office Director and the NZAID representative.
6. The objectives of the workshop were to:
 - Review progress in the implementation of the Biwako Millennium Framework and the recommendations relating to education for children with disabilities arising from the Forum Basic Education Action Plan and the 2003 Pacific Island Forum Leaders meeting.
 - Discuss the draft Convention On The Protection And Promotion Of The Rights And Dignity Of Persons With Disabilities and its implementation.

- Develop policy and programme capacity within governments and national NGOs
- Assess employment opportunities and rehabilitation issues.
- Strengthen government and NSA partnerships at the national level

7. Participants agreed on the relevance and applicability of international and regional commitments such as the Millennium Development Goals (MDGs), Biwako Millennium Framework for Action (BMF), the Education For All initiative, the Forum Basic Education Action Plan (FBEAP) and other pertinent international and regional agreements, as well as the current development of the Pacific Plan. The participants agreed on the following:

- a. The BMF is a blueprint for action at the national and regional level on disability in the second Asia-Pacific Decade For Disabled Persons recognising that it was adopted by UNESCAP in 2002 and endorsed by the Forum Leaders in 2003. The findings of the mid-term review of the BMF be considered by the 2007 meeting of Forum Leaders.
- b. That the Draft Comprehensive and Integral Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities will further enhance the promotion of rights of people with disabilities and the “rights-based” approach to policy and legislation development. It was noted, however, that there should be greater involvement from Pacific Island Country representatives and people with disabilities in the development of international instruments.
- c. Disability is both a cause and an effect of poverty in the Pacific as elsewhere. Poverty is mitigated by the protection of fundamental human rights and social inclusion. Action is necessary in a range of areas to alleviate poverty such as providing opportunities for employment, education, community participation and empower people with disabilities as decision making partners.
- d. Inequalities can be reduced when people with disabilities are empowered to take part in all levels of decision making.
- e. Policy and legislation were identified as key mechanisms for implementing BMF priorities.
- f. Partnerships between governments and Disabled Peoples Organisations (DPOs), and other relevant non-state actors including churches are essential for policy development and the sustainable delivery of services.
- g. It was recognised that DPOs play a crucial advocacy role promoting effective policies and service delivery. It was emphasised that countries which did not have DPOs be supported to develop these.
- h. The media can play a key role in raising awareness and changing attitudes. Countries without DPOs were encouraged to
- i. Disability inclusive approaches are the preferred option to ensure disability issues are mainstreamed into all areas, including education and employment. However, it is acknowledged that there are times where a

“twin track approach” is necessary when disability needs to be seen as a stand-alone issue when people with disabilities need specialised assistance.

- j. The importance of education cannot be overstated, as it is a fundamental human right incorporated in various international commitments. It provides for lifeskills and creates sustainable lifestyle opportunities. Inclusive education, early intervention, and teacher education were recognised as priorities. It was further recognised that the education of children and adults with disabilities and there need to be policy, plans and budgetary allocations for the education of children with disabilities. While inclusive education is ideal, there are cases which require specialised education. Inclusive education will be considered in detail at a forthcoming UNESCO regional workshop. The Forum Basic Education Action Plan (FBEAP) provides a further regional mandate for progressing this issue.
- k. People with disabilities must have a right to decent work. Important vehicles for promoting and safeguarding that right include ILO Convention 159 and other standards, as well as national legislation and policies. ILOs work in the region on labour legislation was noted as was the importance of implementing national policies and legislation. To fully participate in society, people with disabilities need vocational training, employment and self-employment services and should have access to mainstream services, whenever possible. Such services must include business development, credit and marketing assistance for those who are self-employed. Range of work options and emerging models of employment such as supported employment and social enterprises were discussed. Lack of awareness about the abilities of people with disabilities and their rights is among the many barriers to economic participation, however. Further, women with disabilities, those who are socially excluded, individuals with severe disabilities and those lacking basic education face the greatest challenges is finding decent work and accessing the vocational training and services. The potential of partnerships with employers’ organisations, individual employers and trade unions was noted as a way to improve training and increase employment opportunities.
- l. Legislation and policy development are key to protecting and promoting rights and mandating provision of services. Consultation across all sectors and all levels is of crucial importance in policy development to ensure community ownership, acceptance and relevance. Policy provides the opportunity to implement international conventions and make them relevant to national contexts. It was noted that the inclusion of disability in national constitutions is a powerful way of recognising needs and protecting rights. There was a clear need expressed for a regional source of assistance with development of policies and legislation.
- m. There are many constraints and barriers to implementation of policies and legislation including attitudes, cultural practices and traditions, geography and accessibility of remote communities and the lack of human and financial resources.

- n. National focal points are necessary for the effective coordination of programmes and services. However a whole of government approach, by means of the development of national coordination councils on disability, is needed to incorporate disability across all government programmes and key performance indicators on disability should be developed. Disability must be specifically included in national development plans, budgets and bilateral development assistance agreements.
- o. There is a need for adequate data and research to inform policy and service planning and delivery. A variety of approaches for data collection were discussed including sample surveys and incorporating disability questions into national censuses and other surveys such as Household Income and Expenditure Surveys. Further needs were recognised in the coordination of information from other key sectors particularly health and education.
- p. Women with disabilities are particularly disadvantaged and their needs should be addressed and promoted at all levels.
- q. Some indigenous people with disabilities in the Pacific region are particularly disadvantaged and that there needs should be addressed.
- r. The potential of information communications technology (ICT) to empower people with disabilities was recognised in accordance with the strategies and specific targets in the BMF.
- s. Disability is an issue that lends itself well to regionalism. By pooling expertise and working collaboratively regional networks will be strengthened. Regional assistance, coordination and collaboration must be strengthened through regional organisations, development partners, regional NGO networks, particularly the Pacific Disability Forum. It would be desirable to have a regional focal point for disability to coordinate funding, information, regional capacity building, institutional strengthening etc.
- t. A Ministerial meeting on disability should be considered.
- u. UN-EPOC should continue to support the formation of national action plans and the implementation and monitoring of BMF.
- v. The importance of APCD in implementing the BMF was recognised by the workshop. APCD indicated that it is considering establishing a regional mechanism in the Pacific to meet the growing demand for empowerment for people with disabilities and this was warmly welcomed.
- w. There is a need for building the capacity of DPOs to use the rights based approach for advocacy and empowerment to improve the human rights of PWDs at the community and institutional levels and to advocate for policy and legislative change at a national level. RRRT should in partnership with PIFS/PDF/DPOs/donors/development agencies provide technical support to conduct a regional training programme (Regional Community Paralegal Training on the Rights of PWDs) tailored to promoting the human rights of PWDs. The regional advocates should then conduct in-country training to build the capacity of national advocates.

- x. National governments and regional agencies support PDF.

The workshop recommends that:

- i. Governments progress efforts to address the priority areas in the BMF and endeavour to mainstream disability across all sectors, including national development plans and bilateral development assistance agreements.
- ii. Disability remains on the regional agenda and that the outcomes and recommendations of this workshop are presented to the 2005 Forum Leaders meeting.
- iii. Regional agencies and national governments seek greater commitment from donors to mainstream disability in all programmes and make provision for specific disability programmes.
- iv. APCD is urged to increase the involvement of Pacific people in its empowering of people with disabilities.
- v. Technical assistance be provided and made sustainable through an effective regional mechanism involving partnerships between regional organisations, UN and PDF.

Appendix VIII: Terms of Reference: Pacific Regional Disabilities Scoping Study and Review

Assignment Background

The approach to disability has undergone a significant shift in focus from being perceived within a charity and welfare framework to a human rights based issue. Disability concerns have been included in international conventions and understandings. The Convention on the Rights of the Child makes specific reference to including children with disabilities. The NZ Government is taking a lead role in developing a new UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities.

Programmes designed to improve health status and eliminate poverty will be ineffective if they view disability in isolation. A twin track approach, which a) addresses inequalities between those who have disabilities and those who do not and b) supports specific initiatives to empower people with disabilities, is more likely to foster social inclusion, and thus eliminate poverty.

The Biwako Millennium Framework for Action towards an Inclusive Barrier-free and Rights Based Society for Persons with Disabilities in Asia and the Pacific was adopted by governments at a high level intergovernmental meeting in 2002. The Framework is designed as a tool for Governments to guide their policies, planning and implementation of programmes at the national and regional level. Progress towards addressing the priority policy areas and meeting the targets set out in the BMF has already commenced with Governments in the region taking initiatives including writing legislation, protecting rights, developing special education policies, increasing special education capacity, establishing national coordination mechanisms, supporting non-government organisations, reviewing national building codes to address physical barriers faced by people with disability, integrating disability concerns in Education For All initiatives and participating in international and regional initiatives to increase awareness, promote human rights and improve regional coordination.

It is estimated that the percentage of the population in the Pacific with a disability could be as high as 20%. Many people who have significant disabilities face exclusion from economic, social and political structures and systems. Social devaluation and discrimination is commonplace. Myths and prejudice result in abuse, victimisation and alienation of those with a disability. Discrimination takes the form of denied access to education, healthcare and justice systems. Families with a disabled member face major challenges and frequently have little or no support.

Disability is now recognised as a significant issue in the Pacific and is prominent in the Forum Ministers Basic Education Action Plan, was included in the WHO Health Ministers meeting in 2003 and was raised in the recent Forum meeting held in Auckland last year.

Supporting Pacific Island countries to address the needs of people with disabilities in the Pacific was first identified in 1997 as a priority issue for NZODA when “improved support services for people with disabilities” was identified as one of the key areas to be addressed by the Pacific Regional Health Programme. Following on

from a regional disability meeting held in 2001, NZAID funded a three-year disabilities programme to:

- e. Establish a Pacific Disability Information Network to share information and to provide support for people with disabilities in Pacific countries;
- f. Undertake a review of all disability related legislation in Pacific countries in order to assist each country to meet key targets outlined in the UN Agenda for Action for the Asian and Pacific decade of Disabled Persons;
- g. Undertake a needs analysis of people with disabilities in a number of Pacific Countries in order to put in place mechanisms for further support for individuals with disabilities; and
- h. Coordinate a further “Disability in the Pacific Study Meeting” to bring together representatives from those countries where the Disability Identification Survey is being used to benefit people with disabilities and their families.

The project is managed by an NZ NGO, Inclusion International and is due to finish this financial year. Three years after the inception of this programme a number of disability related initiatives now exist in the Pacific. These range from information networks set up through Inclusion International to international organisations, such as ESCAP, working in the area and the formation of local and regional organisations. NZAID wants to move to a more strategic developmental approach that meets our principles and ways of working in order to effectively address the needs of people living with disabilities in the region. In other words, we would prefer to localise our support for disability development by funding an indigenous local organisation, provided there is one in the region with the capacity and capability.

Desired Outcome

A report that gives the *Pacific Regional Health Programme* a *clear, strategic direction* for assistance in the area of disabilities for the next 5 years.

Objectives:

1. Review the Inclusion International Disabilities Project with a view to determining whether the project met its four objectives and completed the activities listed in the project document. In the context of 1&2 the review should recommend whether extending this project should be a priority for NZAID funding as opposed to funding an indigenous provider (local regional agency) directly.
2. Undertake a scoping study/environmental scan and provide a *summary* of key regional issues, donor involvement and activities in the area of disabilities. This summary should identify where there are significant or under-funded gaps.⁵⁴

⁵⁴ This does not require original research. The information is available through ESCAP, the Forum Secretariat, Inclusion International and the Pacific Disabilities Forum.

3. Identify and evaluate the *capacity and capability* of key indigenous regional agencies (both government and non-government), in particular the Pacific Disabilities Forum.

Output

In the light of the findings above produce a report recommending an approach for NZAID over the next 5 years. This should include the what, the how and the where including the method by which NZAID inputs should be managed. The amount of money over the 5 years should not exceed NZ \$300,000 per year.

Methodology

Research in NZ

Sources of information identified, but are not limited to, the following:

1. NZAID reports and papers including the draft NZAID health policy, project documents and reports (these will be provided to the contractor); relevant UN Conventions including the draft Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities; the NZ National Disability Strategy; Forum Secretariat, ESCAP, UNESCO, UNDP and indigenous NGO policies and reports; other donors (government and non-government) policies, approaches and projects especially AusAID.⁵⁵
2. Discussions/communication with NZ Disabled Peoples Association, NZAID, MFAT (Human Rights Division) and the NZHCs, in Suva and Vanuatu; the Forum Secretariat, Suva, ESCAP, Vanuatu; UNESCO and UNDP, Apia and the NZ NGO community especially organisations who have worked with the Pacific (including those funded under the Voluntary Agency Support Scheme).

Field Visits

To meet with JB Munro and relevant staff of Inclusion International, the Disabled Peoples Forum and indigenous NGOs assisted by the Inclusion International Project in Fiji and the Forum Secretariat; disabled peoples organisations of Vanuatu and ESCAP, which is one of the lead players in disability in the Pacific region. The Forum Secretariat (in partnership with the UNESCAP Pacific Operations Centre and Oceania Sub-regional branch of the Disabled Peoples International) is planning a Disability Workshop for June 2005. If this workshop proceeds, it would provide the opportunity for the reviewer to meet with most of the key stakeholders.

In undertaking this analysis:

1. Ensure that stakeholders i.e. the beneficiaries (people with disabilities) of the Inclusion International project and of any future project are consulted during the review and about any future activities recommended for support by NZAID.
2. Pay particular attention to the NZAID policy framework including the crosscutting policies of health, human rights, education, environment and gender in development to ensure they are embedded into the recommendations of report.

⁵⁵ Many of these can be got off the web