



PACIFIC ISLANDS FORUM SECRETARIAT

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FORUM DISABILITY MINISTERS' MEETING

Rarotonga, Cook Islands
21-23 October 2009

SESSION FIVE

**NON-GOVERNMENTAL ORGANISATIONS IN
PACIFIC DISABILITY DEVELOPMENT**

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Purpose

To provide an overview on the roles and contribution of non-governmental organisations in disability inclusive development in the Pacific, including strategies for how these organisations can work effectively with governments.

Background

2. Persons with disabilities in Pacific island countries are among the poorest and most marginalised members of their communities as noted in paper PIFS(09)FDMM.03. The struggling economies of these island nations also inhibit government attention to the presence, needs and concerns of their disabled population which is a minority group in most cases and whose needs are outweighed by the national priorities and agenda.

3. The establishment of organisations of persons with disabilities has increased all over the world since the United Nations proclaimed the International Year of the Disabled Persons in 1981. This increase has been a positive move towards the disability community advocating for their rights, and represents a strong response to the Year's theme of full participation and equal opportunities for persons with disabilities. Such organisations are formally recognised on the agenda of United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities¹ adopted in 1993, with a set of 22 Standard Rules for actualising the theme cited earlier. Rule 18 mentions that it is the responsibility of the state to support the formation and strengthening of organisations of persons with disabilities and to establish ongoing communications with these organisations and ensure their participation in the development of government policies.

¹ United Nations (1994) *United Nations Standard Rules on the Equalization of Opportunities of persons with Disabilities*. New York: United Nations.

4. In Asia and the Pacific region, the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) has been spearheading regional efforts over two consecutive regional disability decades to forge a paradigm shift from a welfare to a human rights-based approach to disability. The first Asian and Pacific Decade of Disabled Persons started in 1993 and concluded in 2002. The second Decade runs from 2003 to 2012. The Biwako Millennium Framework for Action² (BMF) towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific and its supplement, the Biwako Plus Five, are the Decade's policy guidelines on disability to facilitate national policy formulation and implementation on disability.

5. The assessment of achievements made by Pacific Island countries during the first Asian and Pacific Decade of Disabled Persons, 1993-2002, showed that Pacific islands countries lagged behind in the implementation of the Decade's Agenda for Action. This lack of progress has been attributed to lack of information; distance and cost of travel; poorly performing economies; lack of commitment by governments; lack of engagement with NGOs and DPOs³; and the overall lack of voice of persons with disabilities. Some of the areas highlighted by the UNESCAP review where further progress was necessary and related to the subject of this paper include:

- coordination and support of services and programmes provided by NGOs and community and self-help organisations;
- 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 organisations, UN agencies and other multilateral organisations.

6. The establishment of self-help organisations of persons with disabilities and parents' associations is one of the key policy targets of the BMF which states that "Governments, international funding agencies and non-governmental organisations should, by 2004, establish policies with the requisite resource allocations to support the development and formation of self-help organisations of persons with disabilities in all areas, and with a specific focus on slum and rural dwellers. 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."⁴ Whilst national disability policy developed by some Pacific Island countries⁵ have supported the establishment and recognised the role of such organisations, the provision of resources by governments and international NGOs to these organisations have been poor.

² United Nations Economic and Social Commission for Asia and the Pacific (n.d.). *Biwako Millennium Framework (BMF)*. <http://www.unescap.org/esid/psis/disability/bmf/bmf.html>

³ Disability non-governmental organisations (NGOs) are for persons with disability, such as service providers, whereas Disabled Persons Organisations (DPOs) are self-help organisations of persons with disabilities.

⁴ United Nations Economic and Social Commission for Asia and the Pacific (n.d.). *Biwako Millennium Framework (BMF)*. <http://www.unescap.org/esid/psis/disability/bmf/bmf.html>

⁵ Pacific Islands Forum Secretariat. "Disability Inclusive Developments and Progress in the Recent Past in Forum Island Countries: A Status Report". Paper presented at the Forum Disability Ministers Meeting, Rarotonga, Cook Islands, October 2009.

Past Situation and Current Trends

7. The primary catalysts for developing responses to disability issues in Pacific Island countries in the last four decades have been local, national and international non-governmental organisations such as the Red Cross, IHC New Zealand, CBM of Germany and Sight Savers of the United Kingdom. Governments such as Australia, Canada, Japan, New Zealand and the United Kingdom have provided much-needed financial assistance to support the efforts of these non-governmental organisations which mainly target the education and rehabilitation needs of children and adults with disabilities in the Pacific. Examples include the Red Cross Centres in Cook Islands, Solomon Islands, Tuvalu and Tonga; the Able Disable Centre in Nauru; the parents' support group in Kiribati; Vanuatu Society for Disabled People; Prevention, Rehabilitation and Education of Blind Persons and Loto Taumafai of Samoa, and the various disability service providers in Fiji and Papua New Guinea.

8. Numerous single and cross-disability non-governmental organisations were established in the Pacific region during this early period which focused on delivery of services and were managed by able-bodied persons, adopting the view that persons with disabilities must be cared for, spoon-fed, protected and segregated. Persons with disabilities were regarded as recipients of goodwill, unable to make their own choices or determine their own destiny. Also, the strong extended family system in most Pacific Island countries encouraged family members to look after their less fortunate relatives. The association of a disabling condition with ancestral curses, parental misdeeds, witchcraft, shame and fear kept persons with disabilities isolated, neglected, dependent and poor.

9. The international disability rights movement caught the attention of leaders of disabled persons' organisations (DPOs) in Australia, Fiji, New Zealand and Solomon Islands which have been actively operating in this region since the 1990s. Their collective efforts in promoting and advocating for equality, empowerment, recognition and participation of persons with disabilities soon gained momentum as other Pacific Island countries established their own national DPOs to be the voice and representative of persons with disabilities living in their countries. The disability rights movement is about persons with disabilities controlling their own lives with the support they need, and uphold the value that disability must not be looked at in parts but in totality.

10. In March 2000, several organisations of persons with disabilities in the Pacific which are members of Disabled People International (DPI) established a sub-regional office in Suva, Fiji to strengthen their self-help initiatives at the national level through leadership training as well as information exchange across countries in the region. As a result, national DPOs were established in Cook Islands, Kiribati, Papua New Guinea, Samoa, Tonga and Vanuatu. With the support of Inclusion International, an international disability organisation, a Pacific Disability Development Network was established a year later among organisations of and for people with disabilities. The Network initiated surveys to collect accurate data concerning persons with disabilities in countries like Cook Islands, Samoa and Kiribati. As stated in the Inclusion International's Disability in the Pacific report to NZODA in June 2001, it was estimated that at least 5 percent of the Pacific population potentially have disabilities. However, the focus of these surveys was

more towards children and adults who have profound, severe or moderate disabilities, which was estimated at 3 percent of the total population.⁶

11. Disability was not on the agenda of the Pacific Islands Forum (PIF) until 2002 when the Honourable Prime Minister of Vanuatu raised the issue for the first time at the 2002 Pacific Islands Forum Leaders Meeting. This move was prompted by the recommendations adopted by the UNESCAP 7th Special Body on Pacific Island Developing Countries Meeting in Bangkok, Thailand in May 2002. Several United Nations organisations through their Pacific offices have also been actively involved in addressing disability issues in the region including provision of technical assistance in developing national policy on disability, inclusive education, accessible information and communication technology, training and employment, children, youth and women with disabilities, as well as the Convention on the Rights of Persons with Disabilities. Notably, these achievements and initiatives were made possible through the collaborative efforts and advocacy role of disabled persons organisations.

12. The combined efforts of national DPOs and other disability service providers in the Pacific led to a meeting in Fiji in December 2002 where the idea of setting up a Pacific-based regional organisation on disability was discussed. This meeting saw the birth of the Pacific Disability Forum (PDF). The New Zealand Agency for International Development (NZAID) reviewed its funding support to disability programme in the Pacific region in 2005 and the review presented strong recommendations that would give the NZAID Pacific Regional Health Programme a clear, strategic direction for assistance in the area of disability development in the Pacific region for the next five years. PDF was seen at this point to be well placed as a partner to NZAID in this task and subsequently secured a grant funding agreement with NZAID until June 2011.

13. The establishment of PDF as a regional non-governmental organisation and focal point on disability with requisite resources to co-ordinate and promote disability development efforts in the region has been a vital step towards securing representation as well as ensuring participation and voice of Pacific persons with disabilities in the regional fora of the United Nations bodies, the governments of the region, private sector and civil society organisations. This regional organisation can orchestrate the establishment and support the development of disabled persons' organisations, and also serve as a conduit for the dissemination and appropriate application of information, resources and projects to disability-related organisations in the region. Persons with disabilities in the Pacific, speaking with one voice through a regional peak body on disability cannot be lightly ignored in both regional and international fora.

14. Disability non-governmental organisations including DPOs in Pacific Island countries place emphasis on their networks with community groups, other NGOs, business and private sectors as well as governments and inter-governmental organisations. Such networks are utilised for multiple purposes, including fundraising, lobbying, and promotion of an inclusive society for persons with disabilities. Similarly, they work closely with civil society organisations on a range of social issues, such as poverty alleviation, women and gender, health including HIV and AIDS, mental health, environmental pollution and climate change.

⁶ Nowland-Foreman, G. & Stubbs, D. (2005). "Free and Equal: A Review of NZAID Pacific Regional Disability Programme for New Zealand Agency for International Development"

Challenges and Constraints

15. Persons with disabilities are the most marginalised and disadvantaged members of the Pacific society because they are faced with inflexible bureaucracies that cater solely for the 'normal' majority. They are also invisible as they are faced with inaccessible facilities that deny them access to a vast range of goods and services that others take for granted, and worse still, they are faced with attitudinal discrimination that is caused by disinterest, fear and ignorance of disability issues. Persons with disabilities must be valued and respected as fellow human beings who possess the same dreams, needs and aspirations as their non-disabled peers. Reasonable accommodation of their special needs can make them contributing members of, rather than deemed to be a burden to, society.

16. Disability non-governmental organisations in developing countries of the Pacific are in need of development assistance from external sources, including the global civil society. To realise such collaboration, these organisations have to demonstrate intellectual capital, organisational infrastructure and managerial skills as well as proving accountability to meet the requirements of donor organisations. For this to be successfully achieved and mutually beneficial, donor organisations and development partners must invest and commit to building the capacity of such non-governmental organisations.

17. Services for persons with disabilities are often about making such persons well in mind and body; enabling them to contribute to the society they had left before acquiring a disability and equipping them to occupy their rightful places in society.⁷ Unfortunately the vast majority of services provided to persons with disabilities are still rooted in a medical model which often disregards the individual's needs and desires, and whereby a person with disability needs to be treated and cured rather than educated, developed and empowered to live with his/her disability.

18. The disability rights movement and disabled persons organisations face a number of dilemmas in terms of its relationship with governments and more established disability service providers. "To get too close to governments is to risk incorporation and end up carrying out their proposals rather than ours. To move too far away is to risk marginalisation and eventual demise. To collaborate too eagerly with the organisations for persons with disabilities risks having our agendas taken over by them, and having them presented both to us and to politicians as theirs. To remain aloof risks appearing unrealistic and/or unreasonable, and denies possible access to much needed resources".⁸ A better understanding, recognition and appreciation of the important role of DPOs by both governments and organisations for persons with disabilities as key actors in addressing and advancing the disability agenda will help create an enabling, right-based and equitable environment.

Conclusion

19. Being deeply rooted in the charity and medical models, disability services in the Pacific are now experiencing significant pressure from the disability rights movement led by disabled

⁷ Casey, J. "A Brief History of Disability: A View From the Margins." (1999). Center for Independent Living, Dublin, Ireland.

⁸ Mike Oliver and Colin Barnes, Disability Politics and the Disability Movement in Britain: Where Did it All Go Wrong? Coalition, August 2006.

persons organisations, influenced by current global trends and practices. A paradigm shift from charity and medical models to social and rights-based models of disability and service delivery is both necessary and inevitable if Pacific Island governments in partnership with DPOs are to provide equal opportunities, greater recognition and better services to their citizens with disabilities, as well as to comply with the Convention on the Rights of Persons with Disabilities and the Asian and Pacific Decade of Disabled Persons policy framework. The situation of persons with disabilities in the Pacific is also expected to improve as more development partners begin to recognise and promote the need for disability inclusive development, combined with the commitment and support of leaders of Pacific Island governments to this sector.

Recommendation

20. Ministers are invited to:

- (a) **acknowledge** the contributions made by non-governmental organisations in Pacific Island countries to facilitate disability development activities at local, national and regional levels with the support of international non-governmental organisations and development partners; and
- (b) **agree** to strengthen engagement with disability non-governmental organisations and disabled persons organisations at both national and regional levels to build community partnerships and disability inclusive development initiatives in Pacific Island countries.

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