

**Pacific Disability Forum (PDF) and
Australia Pacific Islands Disability Support (APIDS)**

**Capacity Development for Effective and Efficient
Disabled Persons Organisations in
Pacific Island Countries**

Report on Cook Islands component of Research

June 2011

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1. Introduction

A Pacific-wide research program entitled “Capacity Development for Effective and Efficient Disabled People’s Organisations in Pacific Island Countries¹”, commenced in February 2011 with the financial assistance of AusAID. The research process will cover 11 countries and continue to June 2012. Pacific Disability Forum (PDF) is undertaking the research in collaboration with Australia Pacific Islands Disability Support (APIDS). The research team comprises representatives from both organisations and includes in-country researcher(s) nominated by each national member Disabled Peoples Organisation.

In March 2011, the research team undertook activities in Cook Islands. This was the second country to be visited, following the pilot study visit to Fiji in February 2011. The research team comprised two representatives from PDF and two representatives from APIDS and by Mr Robert (Bob) Kimiangatau from the Creative Centre in Avarua, who is a member of the National Disability Council in Cook Islands.

This report summarises the Cook Islands context, the research process, the findings and lessons learned for future aspects of the research.

2. DPOS in Cook Islands

2.1 Cook Islands National Disability Council

Cook Islands’ National Disability Council (CINDC) is a member of PDF. It is one of the founding members of the PDF when it was officially inaugurated in 2004. . The CINDC started as a response to the Biwako Millennium Framework (BMF) in 2001 and its members meet regularly and work closely with the Director, Disability Issues in the Ministry of Internal Affairs and Social Services. The NDC has been provided with an office

¹ This research is being undertaken jointly by PDF and APIDS, and is funded by AusAID.

space by the Ministry, and a volunteer uses the facility on a part-time basis, since a paid staff member completed their contract recently

NDC is intended to take a coordination role for other DPOs in Cook Islands, but noted that this year none of the DPOs had provided copies of their programs to NDC.

NDC was actively involved in the development of the Cook Islands National Disability Policy (2002) and in the Disability Action Team (2005-06) which was intended to implement this policy. In 2009, the Government of Cook Islands implemented the Disability Act and in May 2010 it ratified CRPD and the NDC contributed in various ways to these Government processes, including in an advocacy role, a coordination role and in representing the Cook Islands community of people with disabilities. NDC is currently playing an active role in raising awareness of the CRPD in Cook Islands, working collaboratively with the Government's Disability Director. Their collaboration is highly valued from both sides.

The close relationship between the NDC and the Government appears to work well for both sides and to contribute to effective outcomes, and at the time of this research, there is discussion underway for some changes in the arrangements (see 4. below).

There is potential for the National Disability Council to be consistent with the universally accepted definition of a DPO (organisations run by people with disabilities which advocate for the rights of people with a disability in their country in order to assist them in participating fully in their communities), but at the time of the research, there was not a majority of people with disabilities on the Council.

2.2 Te Vaerua Community Rehabilitation Services Inc

Te Vaerua Community Rehabilitation Services Inc is also a member of PDF. It is a service provider specializing in physical therapy and other forms of support for people with disability in Cook Islands. It's President and one board member have disabilities but the organisation is not established primarily as an advocacy organisation and is not managed by a

majority of people with disability. The organisation believed it was a DPO because it operates completely in the disability sector.

3. Research principles, approaches and methodology

In addition to standard research principles relating to ethical considerations and the selection of a mix of accessible, culturally appropriate tools and processes, the research team approached the methodology with four particular principles in mind:

- We sought to mix the “extraction” of information with opportunities for research participants to learn about their organizations and ways of strengthening them (including opportunities to consider their own definition of capacity, of DPOs and their understanding of and plans for capacity development)
- We sought to focus on understanding the strengths of organizations, how they had been developed over time and how these strengths can be used as the basis for future planning (strengths based approach) and sharing this understanding between participants
- We sought to provide opportunities for DPO-nominated people to build research skills in country through collaborative planning and implementation
- We sought to make the research process accessible for people with a variety of impairments.

The in-country research approach includes the following elements:

- Working collaboratively with PDF member organisations in country so they have a good sense of “ownership” of the research, rather than consider that the research is being done by outsiders
- Emphasis on respecting participants and on putting them at ease during all stages, particularly in meetings and workshops
- Asking core set of questions for participants, adapted to suit different audiences (e.g. “what do you think are the strengths of your organisation?” or “what do you think are the strengths of the organisations with whom you work?”)

- Respecting community protocols and customs
- Ensuring different disability groups are involved and included

The overall research process involves a mix of tools to maximize the chances to confirm any information collected from an individual source:

- Literature survey
- Small group discussions
- Individual meetings
- Workshops
- Case studies (of selected organizations)

The team of researchers participated in a briefing and planning session (by phone) prior to the visit, and then planned together in Cook Islands on the specific program of activities in practical terms (see below).

3.1 Methodology in Cook Islands

From 28 March to 1 April 2011, the research team worked together to:

- Develop detailed plans for in-country implementation, giving specific consideration to the Cook Islands context, including the fact that several organisations considered themselves to be DPOs but did not appear to be consistent with the internationally understood definition of DPOs
- Identify the questions within each research activity
- Allocate responsibilities among team members
- Undertake the research activities with local organisations in the disability sector and their stakeholders, including meetings and a workshop at the end of the week
- Collate findings at the end of the week of activities and identify lessons about how to improve the research process and methodology for subsequent country visits

As noted above, the Cook Islands DPO context is different from other Pacific Island countries, in that while there are two member organisations of PDF which consider themselves to be DPOs, neither of these organisations appear to be consistent with the broader international definition of DPOs. This meant that while meetings could be held as planned, and questions were still used to prompt discussions, the focus of discussions often moved to the issue of how to ensure people with disability were actually involved as leaders and board members of organisations.

Once planning had been undertaken, the following meetings were held during the week:

- National Disability Council – council members
- Te Vaerua – board members and staff
- Creative Centre – board members and staff
- Director, Disability Issues in the Ministry of Internal Affairs and Social Services

A workshop was planned at the end of the week, where stakeholders were invited to participate in order to: share, discuss and confirm findings to date, learn about capacity development concepts relevant to DPOs, and plan for future organisational development. Twenty clients of the Creative Centre (approximately 80% have an intellectual disability) formed the majority of those in attendance, and representation from other stakeholders was disappointingly low (maximum of eight people, but average of around five at any one time). However, as noted below, the poor attendance by other stakeholders provided an opportunity for people with disabilities to raise their own priorities.

Annex 2 provides the list of research activities each day.

Cook Islands was not considered as a candidate for a detailed case study,

In summary, a total of 50 people participated in meetings and workshops. Overall, approximately 65% of participants were women, and approximately 80% of all participants have disabilities.

4. Findings

In summary, questions asked during research meetings and the workshop produced the following issues:

1. Advocacy on the rights of people with disabilities has been very successful in the Cook Islands; the voice of people with disabilities in this process has been valued.
2. Disability service providers want to include people with disabilities on their boards and as staff.
3. There is strong support for people with disabilities from family, community, two service provider organisations and Government.
4. Disability service providers highlight the need for training, mentoring and leadership training for people with disabilities to enable them to manage organizations in future. There is a strong preference for this to be undertaken in Cook Islands.
5. The flow of people between Cook Islands and New Zealand and Australia means that organizations find it difficult to: meet quorum requirements for board meetings; recruit and retain trained/experienced staff members; maintain the continuous delivery of services; achieve all the objectives they set in their plans.
6. Many older people who have lived overseas retire to the Cook Islands with the potential, as they age, to acquire disabilities and become dependent on service support systems.

7. There is a collaborative and respectful relationship between Government and the disability service providers and the National Disability Council .
8. Disability service providers are supportive of assisting the establishment of a DPO (an advocacy organization run by people with disabilities).
9. The Director of Disability is willing to support CI NDC to become the national DPO.
10. Disability service providers want to obtain long-term funding so they can provide ongoing services.
11. People consider that the small population of Cook Islands means there should not be too many separate organizations. There could be too much competition between organizations for funding, for members, for board members and staff members.
12. The Boards of the two major service providers and the National Disability Council are well connected to the private sector and value the support provided by them.
13. It is very difficult and costly for disability organizations to support people with disability in outer islands.
14. When training and services are provided and new ideas introduced, then follow-up activities are very important.
15. Volunteers are very important in both the NDC and in the service provider organizations.
16. There are different views on whether Cook Islands should have its own DPO.

17. There is a commitment for organizations to collaborate and increasing examples of sharing resources.

4.1 Discussion

The context in Cook Islands in relation to DPOs reflects the particular mix of history, personalities, events, influences, geography, culture and issues which are specific to Cook Islands. There is clearly a great deal of support for people with disabilities at several levels (family, community, private sector, service provider, individual professional and Government) and this is demonstrated in the relatively good level and quality of services provided compared with some other Pacific Island countries. There is also a strong advocate for disability rights within the Cook Islands Government – the Director, Disability Issues – who has achieved a great deal in terms of policy development and coordination across Government.

A very small number of people with disabilities have played leadership roles in Cook Islands disability organisations over many years. These leaders have participated actively and contributed significantly in the achievements that have been made in Cook Islands, especially in relation to the signing of the Convention on the Rights of Persons with Disability and its implementation. There is considerable scope for more people, especially younger people, to participate in decision-making and to manage their own organisations to represent people with disabilities and to advocate for the rights of members. There are a number of reasons why not many people have been involved so far. Stakeholders noted the following reasons:

- Office bearers of existing organisations have often held the roles for many years
- Office bearers in existing organisations consider there are few obvious emerging leaders with disabilities who could take over their roles without them receiving considerable training, coaching, mentoring or other support, which has yet to be formally organized,

despite good intentions (“*we can design the best program in the world, but without the right person, it won’t work...and in this context we can’t find the right person*”)

- People with disabilities themselves, especially younger people or those who are not already actively involved (emerging leaders), had not considered there were opportunities available for them to be directly involved in disability advocacy activity or organisations
- The population of people with disabilities in Cook Islands is relatively small, as many families take family members with disabilities to New Zealand or Australia to be able to access a broader range of services
- While the population of Raratonga is higher than the outer islands and therefore a greater source of potential DPO office bearers, the inclusion of people from outer islands in DPOs is very challenging because of accessibility and high cost issues

The issue of the definition of a DPO mentioned above is clearly related to the perception by some (but not all) current office bearers and by some (but not all) people from service provider organisations that people with disability in Cook Islands who are not already involved in DPOs, do not currently have the “capacity” to take over the officer bearer roles themselves. Thus the idea that DPOs could be managed by people with disability now or in the short-term future is somewhat challenging.

However, it is clear that several people are supportive of the concept and the principle. The opportunity for people with disabilities to “step up” to office bearer roles in existing organisations or to set up a new organisation, involves some complexity, but there is goodwill and some degree of interest, so clearly some scope for this to occur. For example, an NDC office bearer indicated that if training could be provided to young people, then they could take up a role in the Council, and Te Vaerua noted that if they were able to continue to successfully “get people out of bed and functioning” then they could be actively involved in managing their organisation. The Director of Disability Issues from the Cook Islands Government offered to provide capacity development assistance next year

for young people with disabilities so they could take up roles as office bearers

The Constitution of the NDC states that 75% of board members should be people with disabilities and 25% could be made up of family members and others. Since its establishment in 2001 however, few people with disabilities have been appointed and those who have, have held roles for many years. In terms of organisational objectives, the NDC aims to strengthen its board and its office capacity so it is more able to achieve its objectives, such as produce a regular newsletter and engage more effectively at community level and with partner organisations. There is interest in establishing a group of Women with Disabilities but this has not been successful to date.

The relationship between NDC and the Government's Director of Disability Issues is largely positive and constructive. The Director considers that NDC should operate as a pure non-government organisation, which is independent, self-managed and plays an advocacy role to the Government. She sees that NDC has the potential to be a DPO but that people with disability currently do not have sufficient capacity to run their own organisation. She offered to assist with training potential office bearers in governance issues and considers that next year, NDC could become a DPO. Those members of the NDC interviewed for this research described the tension between finding "champions" who could advocate effectively and professionally at senior levels, and allowing people with disability to emerge as leaders in their own way and time. On one hand, NDC considered that it would be preferable to obtain greater support from the Government to enable the NDC to be active, professional and effective, but on the other hand, the Government considered that NDC should be more independent rather than increasingly dependent on Government. The Government considered that NDC had the potential to build on its strong advocacy skills and increase its management and day-to-day effectiveness.

The existence of several organisations focused on disability services in Cook Islands was raised as an issue, albeit not directly relevant to the

concept of DPOs. The issue is relevant though, to the concept that in a country with such a low and transient population, there is concern about the existence of multiple organisations. The establishment of Te Vaerua in 2006??, following the completion of the term of the Disability Action Team, initially raised concerns about potential duplication of service delivery between them and the Creative Centre. In recent times, this risk has been perceived to be reduced and there is increasing coordination and cooperation, and a clearer distinction made between the different services offered. Both organisations are predominantly service providers.

As only eight stakeholders attended the research workshop which was organised for the end of the week's visit, the planned schedule did not proceed. Instead, twenty members of the Creative Centre were brought to the workshop venue, and three groups were formed (comprising all those in attendance) to discuss general issues about advocacy for people with disability in Cook Islands. During these group discussions, participants directly raised a request that a new organisation be formed to be made up of people with disabilities, to advocate for the rights of people with disabilities. Several participants said they had been waiting for 10 years for the opportunity to raise their voice and to "put their hand up", and this workshop gave them the confidence to do so. The participants directly asked the researchers to facilitate a planning session with them to start this process, at the workshop venue, straight away. In response, the researchers facilitated discussions and these led to: shared identification of some organisational objectives, some nominated office bearers and an action plan for a new organisation. This group has subsequently met again, but there is no clarity yet on the organisation's status.

4.2 Summary

The situation of organisations operating in the area of disability in Cook Islands is complex and different from Fiji and other countries known to the researchers. There are some clear strengths in the sector in Cook Islands including:

- a number of organisations which are committed to the principles of rights for people with disabilities and have skills relevant to advocacy
- a relatively supportive environment for organisations operating in the sector
- a strong advocate within Government for the rights of people with disability
- interest in a DPO which has a majority of office bearers who have disabilities, recognising that the CINDC constitution already provides for this

For the broader research, the case of Cook Islands offers the following lessons:

- a great deal can be achieved through a collaborative relationship between Government and disability NGOs, but care needs to be given to delineating the respective roles and mutual expectations
- service providers may sit along a spectrum from a medical, charity, social or rights-based approach to disability but are not necessarily skilled in knowing how best to enable self-leadership by people with disability in advocacy terms
- DPOs in small countries may struggle to find sufficient numbers of people with disabilities to be able to sustain active and effective organisations, and without explicit action to achieve this, the default position is that senior office bearers will remain in positions in the long-term and younger and emerging leaders will not see opportunities for themselves
- perceptions about the kinds of skills needed for successful operations of a DPO can influence the chances of people with disability (who have not had the opportunities to gain relevant experience) from achieving leadership roles, especially when some people hold office bearer roles for extended periods.