

**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 Papua New Guinea component of Research**

*October 2011*

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### **Note re DPO and SHO terminology**

*NB The research team found that both the terms disabled persons organisation (DPO) and self help organisation (SHO) were used in PNG. Each organisation has a preference for one or the other title, reflecting their original choices (SHO was a term used by UNESCAP as one of its 12 policy areas on the Agenda for Action during the Asian and Pacific Decade for Disabled Persons, 1993-2002; whereas DPO has become more widely used since then) but the meaning is interchangeable. This report uses the term preferred by each organisation and recognises that the terms have the same meaning. When writing about DPOs generally, the term DPO is used.*

## **1. Introduction**

A Pacific-wide research program entitled “Capacity Development for Effective and Efficient Disabled People’s Organisations in Pacific Island Countries<sup>1</sup>”, commenced in February 2011 with the financial assistance of AusAID. The research process will cover 11 countries and continue to June 2012.

Papua New Guinea is the fourth country to be visited as part of this research (after the pilot was undertaken in Fiji, the research has been undertaken in Cook Islands and Samoa).

The PDF/APIDS research team worked with two Papua New Guinean researchers from the PNG Assembly of Disabled People (PNGADP), making a team of six researchers. The team worked together from 27 July to 4 August 2011 and held meetings in Port Moresby, Goroka and Madang. Team members included:

- Ipul Powaseu, PNGADP
- Richard Mandui, PNGADP
- Katabwena Tawaka, PDF
- Angeline Chand, PDF
- Robyn James, APIDS
- Deborah Rhodes, APIDS

This report summarises the research process and findings from Papua New Guinea.

## **2. DPOs in Papua New Guinea**

In summary, the current DPO situation in Papua New Guinea has the following features:

- A relatively recent history of DPO formation, which started following a workshop run by DPI Asia Pacific through its Oceania Subregional Office in 2002 in Lae (see below)
- A national cross-disability DPO, PNGADP which:
  - Is a registered non-government organization

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<sup>1</sup> This research is being undertaken jointly by PDF and APIDS, and is funded by AusAID.

- has an Executive Committee comprising 5 officials
- has three paid staff and volunteers
- operates from office space provided by the Department of Community Development<sup>2</sup> with equipment funded by partner agencies, including APIDS
- is actively involved in PDF
- operates at the national level in Port Moresby and makes considerable effort to link up with provincial and district level self-help organizations, (SHOs) (this term is preferred by some in PNG)
- developed an agreement in 2011 to work towards a national structure for DPOs across the country including plans for 20 Provincial level organisations to be established
- works closely with the Department of Community Development and has strong links with the then Minister, Dame Carol Kidu<sup>3</sup>, who has a commitment to disability issues
- works collaboratively with some service providers

The research team also found that a range of non-profit organizations and churches provide services for people with disabilities and some have operated over many decades. Most use medical or charity models to underpin their work, although several are now beginning to be aware of the rights based approach and are considering ways to support the development of DPOs.

### **2.1 History of DPOs/SHOs in Papua New Guinea**

The initial impetus for the development of DPOs in PNG was a workshop organized in Lae in 2002 by DPI Asia Pacific through its Oceania Sub-regional Office based in Suva, Fiji where the term SHO was introduced by the workshop facilitators to refer to organisations led and managed by people with disabilities themselves. Setareki Macanawai who was then the DPI Asia Pacific Vice Chairperson responsible for the

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<sup>2</sup> At the time of the research, the office did not have electricity supply, so PNGADP was operating from a small office at a sheltered workshop on the Port Moresby hospital site.

<sup>3</sup> During the research process, a change of Prime Minister and Government appeared to result in the Minister for Community Development losing her role – this is a great loss to the disability sector as Dame Carol was a significant champion for disability rights

Oceania Subregion and Sam Vilsoni from Fiji were facilitators at this workshop along with the late Topong Kulkhanchit who was the DPI Asia Pacific Regional Development Officer. Following this meeting, which included people with disabilities from several provinces, the Papua New Guinea National Assembly of Disabled Persons (PNGNADP) was established and the Board members elected. A small number of participants who attended this workshop established SHOs at district level when they returned to their respective districts. Examples include: the Madang Disabled Self Help Group and the National Capital District SHO and then later, Pari Village SHO (2006). PNGNADP became a member of DPI in 2002 and was based in Lae with the support of the Rehabilitation Unit at the Lae Hospital.

Between 2002 and 2007, PNG representatives participated in various Pacific regional disability meetings. PNGNADP is one of several national DPOs from the region that established the Pacific Disability Forum, and is therefore considered a founding member. PNGNADP was actively involved in the Capacity Building workshop for Self-Help Organisation of Persons with Disabilities (CBSHOD) conducted in Port Moresby in 2007 supported by the Asia and Pacific Development Centre on Disability (APCD) and DPI Asia Pacific. Many Pacific Island countries sent representatives from their respective DPOs to this regional training workshop. The PNGNADP later became known as the PNGADP when it was officially launched in 2009, when an election of people was undertaken and the organisation established in Port Moresby.

Between 2007 and 2009, PNGADP worked on developing its structures, systems, office accommodation, networks and leadership style. The challenges of geography, transport, lack of access to experienced organisational managers or experienced officials, lack of official or systematic organisational support, as well as financial mismanagement contributed to steady but sporadic progress.

Until 2009, the dominant advocacy voices in the disability sector in relation to disability policies in PNG, were the leaders of a number of service provider networks, particularly Red Cross and Callan Services which both operate across multiple sites and services, as well as St John for the Blind and Red Cross School for the Deaf. They provided little support to PNGADP at the outset, but some are increasingly collaborative and supportive.

In 2009, Ms Ipul Powaseu became Chairperson of PNGADP, following encouragement from the then Minister for Community Development, Dame Carol Kidu. Ipul's experience in research, including corporate services in the research sector, and her strong leadership skills made her well qualified to lead the emerging organization to its next stage of development. One of her first achievements was to complete the organisation's first strategic plan. This strategic plan is now regarded as a valuable

guiding document for PNGADP, is well linked to the GoPNG's Disability Policy, appropriately reflects CRPD, and is comprehensive enough to provide a framework for PNGADP development for the medium term.<sup>4</sup>

In 2010, PNGADP commenced its outreach work to Provinces, to raise awareness of the rights of people with disabilities. It is important to note that this means there is only recent and short experience of this kind of work in PNG.

PNGADP was provided with office space by the Department of Community Development in 2008, but because of power disconnection and renovations, it was not available to them since 2010. During the research, PNGADP was operating out of a one-person office attached to a busy and noisy "sheltered workshop" in the Port Moresby hospital grounds.

During the 2000s, a number of SHOs emerged and some experienced difficulties and fluctuating levels of activity, depending on a range of factors such as individual leadership and group commitment issues and funding or financial issues.

As SHOs emerge in PNG as a means for people with disabilities to determine their own priorities and raise their own voice in advocacy, there are signs of tension between them and some service provider organizations, although there are also signs of good quality collaboration and shared values. The tensions arise when people with disability speak up for themselves and their own priorities rather than remain the "subjects" of decision-making by others. Reflecting experiences in other countries, the ways in which these tensions and partnerships are managed in PNG in the next few years will influence the longer-term success of any collaborative efforts in relation to advocacy between self-help organizations and service providers.

Beyond PNGADP, one national single-disability SHO has been established in the last decade: PNG Blind Union. A meeting with members of the Blind Union was included in this research process, although unfortunately not a meeting with the Board. Members reported that the organisation has a strong board in place. They noted that board members have had training in good governance and transparency, and that they have skills to manage the organisation well. They noted that there is scope for them to strengthen their organisation, for example through establishing an office and expanding membership nationally and organising more opportunities for training. The Blind Union is active within PNGADP and has partnerships with other organisations within and outside PNG.

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<sup>4</sup> The Government of PNG has signed CRPD but at the time of the research, has yet to ratify it, as it is considering the implications of ratification for Government systems.

During the research process, there were tentative initial signs that an association for the deaf could be developed.

### **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 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 SHO-nominated people to build research skills in country through collaborative planning and implementation<sup>5</sup>
- We sought to make the research process accessible for people with a variety of impairments, depending on the support of PNGADP and SHOs themselves to be as inclusive as possible.

In practice, the in-country research approach includes the following elements:

- Working collaboratively with the SHOs 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 SHO?” or “what do you think are the strengths of the SHOs with whom you work?”)
- Respecting community protocols and customs
- Ensuring different disability groups are involved and included

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<sup>5</sup> This is an objective in the research process overall, but in PNG, the team was joined by a researcher (Ms Ipul Powaseu) who is already highly experienced and whose expertise contributed to the quality of the process in-country.

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

- Literature survey (completed in early 2011)
- Small group discussions
- Individual meetings
- Workshops
- Case studies (of selected organizations)

### **3.1 Methodology in Papua New Guinea**

From 27 July to 4 August 2011, the research team worked together to:

- Develop detailed plans for in-country implementation of the research in ways that are consistent with the research objectives, principles and methods. Specific consideration was given to the PNG context, including diversity of languages, the variety of organisations, many of which are in the process of emerging at the time of the research, and challenges of transportation between meetings
- Confirm the questions which would be used within each research activity, based on linguistic and cultural issues (affecting translation, meanings of words etc.)
- Allocate responsibilities among team members in order to maximize the quality of the research process and achievement of objectives
- Undertake meetings as per the agreed plans, including trips for half the team to Eastern Highlands Province and the other half to Madang Province
- 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 Papua New Guinea is by far the largest country in which the research is being undertaken, it was agreed by PDF and APIDS, that a slightly longer time frame be allowed (i.e. 7 days rather than the average 5 days) and that two provincial visits would be undertaken, one to Madang and one to Goroka. The six-person team split into two sub-teams for the provincial visits.

Three inter-related factors meant that the research team needed to take a flexible approach to the extent of inclusion of SHO participants. First, PNGADP is based in Port Moresby in the National Capital District (NCD), where there are a number of SHOs operating at various levels of activity and formality, and even within the city, accessibility to transport is difficult, so meetings are hard to organise. Second, Port Moresby is not accessible to other parts of the country where SHOs are emerging, so flights are

required to reach other locations, and within provinces, travel is also challenging, time consuming and expensive. Third, while PNGADP has plans to develop a national structure, initial elements are only just emerging and the full structure does not yet exist (see Section 4.1.3 below).

The Papua New Guinea research team members had selected Madang and Goroka as suitable sites for visits because these were considered to have strong emerging SHOs as well as cooperative service providers who could support the design process, including organizing meetings, accommodation, transport etc.

A timetable of meetings for board members, staff and members of DPOs, as well as other stakeholders was prepared by the Papua New Guinea research team members. Following discussions on the first day, this timetable was adjusted and confirmed.

Annex 1 provides the list of research activities each day and the groups and individuals met. Annex 2 provides the outline of the workshop undertaken on Wednesday 3 August 2011. In summary, approximately 70 people participated in research meetings and workshops. Around 30% were women, and approximately 80% of all participants have disabilities.

### **3.2 Model for considering elements of capacity in Papua New Guinea DPOs**

While there are many models for understanding organisational capacity, the Baser and Morgan (2009) model has been selected for framing analysis in this research<sup>6</sup>. This model, based on extensive international research, suggests that capacity comprises the following five elements:

#### **CAPABILITY TO COMMIT AND ENGAGE**

Includes the following:

- the ability to encourage mindfulness (being thoughtful about the impact of words and actions)
- the ability and willingness to persevere (to keep to goals and actions even when facing difficulties)
- the ability to aspire (to be ambitious; to dream)
- the ability to embed conviction (to make sure everyone is committed to working hard towards the shared goals)

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<sup>6</sup> The model was not provided to participants in the research, but was shared with the research team members to assist with analysis.

- the ability to take ownership (to make sure that any plans to change the organization and its work are completely “owned” by the organization itself)
- the ability to be determined (to make strong efforts to achieve goals despite any challenges or setbacks)

### **CAPABILITY TO CARRY OUT TECHNICAL, SERVICE DELIVERY AND LOGISTICAL TASKS**

Includes the following:

- the ability to deliver services
- the ability to plan strategically (to reach longer-term objectives, not just short-term day-to-day work)
- the ability to manage the implementation of all the plans effectively and efficiently (with consideration given to different definitions of effectiveness and efficiency)
- the ability to manage the finances (in ways which comply with local laws, practices and values)

### **CAPABILITY TO RELATE AND ATTRACT**

Includes the following:

- the ability to buffer the organisation or system from intrusions (to protect organizations from outside destructive or distracting events or people)
- the ability to earn the trust of others, such as donors and partners
- the ability to combine political neutrality and assertive advocacy (to be able to achieve goals confidently without upsetting politicians and others through too much blatant criticism)

### **CAPABILITY TO ADAPT AND SELF-RENEW**

Includes the following:

- the ability to improve individual and organisational learning
- the ability to foster internal dialogue (to provide chances for people to talk with each other openly about things that are happening and what is planned)
- the ability to reposition and reconfigure the organisation
- the ability to incorporate new ideas
- the ability to map out a growth path

### **CAPABILITY TO BALANCE DIVERSITY AND COHERENCE**

Includes the following:

- the ability to communicate
- the ability to build connections (to work collaboratively with other organizations)

- the ability to manage diversity (to make the most of different ideas from people and strengths within the organization)
- the ability to manage paradox and tension (to work out how to deal with information which is opposite from other information, and how to deal with people who have different ideas)

## 4. Findings

The themes listed below emerged from an analysis of notes from all meetings. The themes were collated by the research team prior to the workshop on 3 August. At the workshop, participants discussed each theme in detail and made a number of revisions and additions before confirming that all statements listed below are an accurate description of the capacity development situation of SHOs in PNG at this time, consistent with the research methodology.

1. **There is strong leadership at national level in PNGADP. There is emerging leadership potential in SHOs operating at provincial and district levels.**
2. **There is good family support for people with disabilities, including those who are leaders and office bearers in SHOs.**
3. **Service providers are supportive of and contributing to the development of SHOs at district and provincial levels.**
4. **People place value on being a member of self-help organizations.**
5. **When people with disability learn about their rights, it empowers them to stand up, speak out or organize themselves into groups.**
6. **The issue of disability is getting an increasing profile at the national level and people with disability are increasingly aware of their rights: PNGADP is contributing to these changes.**
7. **The Government of Papua New Guinea through the Department for Community Development, and particularly the work of Dame Carol Kidu<sup>7</sup>,**

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<sup>7</sup> The day after this workshop was held, a change in Government leadership in PNG resulted in the departure of Dame Carol Kidu as the Minister for Community Development. This is a very sad loss for disability issues in PNG, as Dame Kidu has been a champion for some years. Her significant contribution to disability rights is clearly highly valued by people with disability and their organisations in PNG.

**recognise disability as a cross-cutting issue, work collaboratively with others and allocate money through its development budget for disability activities.**

- 8. There is a strategic plan which guides PNGADP and this includes development of a national structure.**
- 9. Data collection about potential members and their needs is a priority for many people and organizations in the disability sector. Despite valiant efforts, the recent national census did not include questions about disability.**
- 10. Self help associations want ongoing training for their officials and members on a range of topics including governance, administration, leadership, financial management, monitoring and evaluation, advocacy and CRPD.**
- 11. There is a shared commitment to increase systemic advocacy in relation to rights as included in CRPD.**
- 12. There is increasing connection between the different associations across PNG despite great challenges in communications and transport.**
- 13. Although there is inadequate funding for self-help associations across the country, they are still emerging and growing.**
- 14. SHOs increasingly understand and apply the rights based approach and some service providers are beginning to be aware of this approach and to consider its implications for their work. Many service providers currently use a medical or charity model to approach their work.**
- 15. To help them strengthen and grow their organizations, some self-help associations are seeking volunteers or other sources of expertise in relation to office and program management as well as organizational governance.**
- 16. SHOS are recognizing the importance of governance integrity and still seek assistance to enable them to understand how to achieve this.**

#### **4.1 Discussion**

This research attempts to understand perceptions of DPO capacity by DPOs themselves and their stakeholders, as well as perceptions of changes in capacity over time and factors which contribute to effective change. Importantly, this research did not attempt to “measure” DPO capacity using any externally determined tool. This section discusses the findings listed above, within an understanding of the history of PNG DPOs, using a strengths based approach and the capacity elements identified in 3.2 above.

As all research in PNG confirms, the country is a highly complex context for any development issue or process. PNG has a great diversity of cultures and languages, highly varied topography which influences communications and transport, and complex government structures (i.e. national, provincial, district and local level government levels). Importantly, it has the largest population of any country in the Pacific region. For people with disability in PNG, who have largely been ignored socially, officially and in most development processes at all levels until the last decade, the context presents both myriad opportunities and challenges.

The PNG context has a significant influence on the current capacity of SHOs. In summary, this context includes:

- relatively recent and limited understanding of the rights of people with disabilities
- only recent experience of the application of the rights based approach in advocacy and other work
- dominance of service providers, using a medical or charity model, in the disability agenda until the last decade
- relatively recent support from the Government of PNG for SHOs
- challenges of communications, links and coordination between SHOs at different levels (district, provincial and national) because of distances between locations
- relatively recent emergence of SHOs reflecting little early history of engagement with international rights based agenda
- cultural taboos on people with disability and strong community perspectives that people with disability are not able to be independent, to organize themselves and to determine their own priorities.

The history of SHOs in PNG reflects to some extent the history of other community based or non-government organisations. Organisations often emerge under a particular leader or small group of leaders, attract attention and partners and then for a number of interacting reasons, become less active and effective. Sometimes these organisations re-emerge over time, and new leaders make their own distinctive mark. The history of

DPOs confirms this experience, with the re-emergence of PNGADP in the past 2 years and a number of district level DPOs in various stages of “decline” or potential re-emergence.

Overall, PNG SHOs have some important strengths in capacity terms, and they reflect a relatively recent history of SHO development. Current strengths are the result of many factors, some of which come from within the organizations themselves and others which come from national, regional and international sources, such as the influence of DPI Asia Pacific through its Oceania Sub-regional Office and the broader international disability rights movement. Papua New Guinea cultural values about leadership and the concept of organisations are also relevant in that they influence the nature and style of DPOs

In summary, using the capacity framework (see 3.2), and based on findings discussed below, Papua New Guinean DPOs have a number of capacity strengths, including:

- leadership at the national level in the form of the board of PNGADP
- the ability to motivate and bring people together to identify shared objectives
- the ability to develop a plan and use it as a framework to guide action
- the ability to work collaboratively with the Government of PNG and service providers
- the ability to conceptualise a complex national structure to maximise representation, recognise diversity and emphasise the emergence of locally driven organisations
- the determination and ability to promote the disability rights agenda
- the ability to organize a Board and its meetings and to appoint staff members
- the ability to build connections and earn the respect of others, including partners, Government representatives, communities, other NGOs and donor agencies
- the ability to advocate, through articulating rights based concepts and implications for organisations and for changes in approaches and practice
- the ability to improve individual and organisational learning, particularly by maximizing opportunities for members to attend training, workshops, committee meetings etc.

#### **4.1.1 Leadership**

The emergence of DPOs is highly dependent on the courage of individuals to take leadership roles at various levels. As is the case globally, leadership is a complex issue in itself, with personal qualities and competencies required across a range of areas. Leadership can be expressed differently in different cultural contexts and can operate

differently in either supportive or hostile environments. In PNG, at the time of this research, there are elements of support and elements of tension in the area of disability rights, so leaders need particular strengths to achieve success and there are many challenges to address. Compared with the other large Pacific Island included in this research, Fiji, there is a relatively recent history of leadership in DPOs in PNG. This, among other factors, means that the nature of the organisations and the style of leadership are noticeably different.

Several respondents in the research identified that a key contributor to the success of PNGADP in recent years has been strong leadership, in terms of the current Board and particularly the Chair person. Staff of PNGADP noted that its Chair person and Board Members had contributed to good motivation levels and were successfully raising the profile of the rights of disabled people in PNG. The strengths of the current leaders of PNGADP particularly include the abilities:

- to empower other people with disability, both in Port Moresby and through visits to provinces and districts
- to collaborate with Government and other agencies to bring about shared objectives
- to articulate a vision for people with disability in PNG
- to set an example to other potential leaders that people with disability can be leaders

Beyond the national association, there is a good understanding about the critical but sometimes precarious role of SHO leaders at local levels. There is also good understanding about the high expectations that are sometimes placed on leaders and the challenges they face in managing a diversity of issues in policy, organisational, relationship and practical ways. The sheer challenge of organising meetings of people with disabilities is significant in PNG, given the distances between places, the lack of accessible transport and the high cost of travel. One respondent noted that *“when funds are available for transport to a meeting, such as when there is a visit by the Chair of PNGADP or a research such as this, then SHOs can meet and be strong.”* The implication of this is that when there are no funds for transport, members of SHOs simply are unable to meet, to organize etc.

While some service providers are aware of the strengths of one or two leaders, some respondents in this research do not necessarily share the view that there are strong leaders in the disability sector at community level. For example, one stated *“they need good leaders”* and *“their leadership is not very strong”*. Given the relatively recent history of SHOs in PNG, it may take some time before broader leadership strengths

emerge. Without significant community acknowledgement of the rights of people with disabilities, the roles of senior people with disabilities in demonstrating leadership are particularly important. Their achievements provide encouragement for emerging leaders and their mentoring and coaching, as fellow people with disability, is potentially more relevant and powerful than that which could be provided by able-bodied people.

During the research process, it was pointed out several times that people who have been born in PNG with a disability have often been excluded from education, so are not likely to have developed the confidence or skills to take up a leadership role without a great deal of support. People who have been able to attend school and gain skills in a workplace setting, or those who have obtained their disability later in life, are more likely to emerge as potential leaders.

#### **4.1.2 Strategy**

In 2009, PNGADP office bearers, staff and members, both men and women, produced a comprehensive and impressive Strategic Plan. Those who are aware of the Plan commended it for its value in providing a solid foundation as well as a set of clear objectives for the organisation. It links strongly with the Government's Disability Policy, which helps to maximise coherence and cooperation. PNGADP's Chair sees the Strategic Plan as a source of information on CRPD to guide capacity development of PNGADP, as well as a roadmap to take PNGADP in the right direction. It is seen as a way to assist the Government of PNG with its commitments under the Disability Policy, with particular focus on the elements that PNGADP can contribute, such as:

- capacity development of organisations and leaders of SHOs
- advocacy on CRDP
- monitoring and evaluation of services
- implementation of policies relevant to members

#### **4.1.3 Structure**

Recognising the reality of PNG's geography, size and government systems, PNGADP has made a decision to develop a national structure of SHOs, whereby the national body itself is made up of representatives of provincial level organizations and single-disability (known as "line-disability") organisations in PNG. The intention is that these provincial level SHOs would comprise representatives from district level SHOs. Each level of SHOs would thus be an umbrella for the next level below. The feasibility of this structure has not yet been tested and at the time of the research, there are minimal signs of the proposed structure emerging (some district level SHOs currently exist and

the research team found a potential provincial level SHO in Madang). The process rightfully assumes that developing these groups would be the responsibility of people with disabilities themselves and that the associations will emerge gradually, with support provided at each level by respective partners and the PNGADP network. It is envisaged that the process will take time rather than be rushed or forced from the national level. It may be possible that such a structure takes many years to emerge or that a different structure may be deemed suitable in the PNG context, if this structure does not eventuate.

#### **4.1.4 Membership of SHOs**

Respondents frequently noted that members are a strength of PNG SHOs. There were also frequent references to the value placed by people with disabilities on their membership of SHOs. For example, one office bearer in Madang said: *“when we get together, I have a sense of courage and purpose”* and a member in Port Moresby said: *“we have just come out of hiding and have realized that we are part of not just a PNG group, but a global movement. We thank PNGADP for finding us and bringing us out.”* One of the new office bearers in Henganofi SHO said: *“I have realized I had potential and I didn’t use it, but now I am involved in setting up this organisation, I am empowered and strong.”* The emergence of more SHOs in PNG at various levels means that more people with disabilities are likely to share this sentiment. The leap for people to move from feeling isolated, disempowered and excluded to feeling empowered, engaged and part of a group is highly significant. This is one of the clear strengths of SHOs and has the potential to contribute to stronger SHOs in future. *“We, people with disabilities, must talk straight and come out and make our organisation strong.”*

The inclusion of an office bearer who represents and works with women with disabilities was noted as a particular strength in PNGADP. Both men and women are included in those SHOs included in the research, as office bearers and members. However, there were certainly more men than women participating in the research meetings (approximately 30% women) and the workshop (approximately 25% women).

The existence of PNGADP and other SHOs is seen as a great opportunity for members to be recognised and to “raise their voices to the nation.” One respondent noted: “there has always been people with disabilities in PNG, but only now that PNGADP has started, the issues and our profile has been raised in the country. Now we are seeing lots of positive developments and our advocacy is raising confidence of people with disabilities. This is encouraging for me.”

At district levels, members saw a range of benefits of being a part of an SHO. For example SHOs could:

- help them to become self-reliant
- give them a sense of not being alone
- help them to find equipment
- collect data to find out about the needs of people with disabilities in their location
- empower each other
- give access to information (e.g. about CRPD)
- help us make new friends and partners to support us in our efforts.

#### **4.1.5 Awareness of rights and rights based approach**

There are clear signs that office bearers and members of SHOs are aware of the rights of people with disabilities and have begun to use a rights based approach in their advocacy and representational work. Many respondents noted that one of the strengths of the SHOs is their understanding of CRPD. It is only within the last decade that there has been any understanding among people with disability in PNG about their rights and this awareness remains relatively low across the broader community. In a context where there has been negligible official or community recognition about the rights of people with disability, including the right to organize themselves, emerging SHOs themselves have largely lacked support or recognition, and have thus struggled to exist and grow. This situation has resulted in little SHO development until recently.

The application of the rights based approach is also beginning in PNG. The development of SHOs is one illustration of this application, and there are many opportunities to expand in the future, so that the rights based approach can inform systemic advocacy efforts, organisational development, partnerships with others and awareness raising processes.

Until the last two to three years, the dominant perspective on the situation of people with disabilities Papua New Guinea more broadly has been expressed by service providers using medical or welfare/charity models. Under these models, medical professionals, disability service providers or carers/parents make most decisions about the lives of adult people with disabilities. These organisations have been the most dominant influence on Government disability policy until the most recent version, where greater recognition has been given to SHOs and the rights of people with disabilities rather than issues about the delivery of and access to services. During the research workshop, there was some discussion about whether service providers understood and applied the

rights based approach, and it was concluded that some do and some do not. There is clearly scope for more service providers to increase their understanding and to apply rights based approaches to their work.

#### **4.1.6 Relations with disability service providers and community**

The research process identified several examples of good relationships between SHOs and service providers. In particular, the significant support provided by the Eastern Highlands Disability Committee (representing service providers, government representatives and SHOs) for the emerging Henganofi SHO (see Annex 3), is a good example of collaboration within a rights based framework. Also, at the request of PNGADP, the research process was considerably assisted by people from service providers in Goroka and Madang in the organisation of accommodation and provision of transport. The National Disability Resource and Advocacy Group (NDRAG) in Madang also has a positive and collaborative relationship with PNGADP.

Meetings with service provider organisations provided a very good understanding of the disability context in PNG. At the national level, a National Board for Disabled Persons represents service provider organisations and this is often considered to be the organisation which represents people with disabilities themselves, rather than organisations which provide services to people with disabilities.

There is considerable potential to expand on existing positive relationships over time, while managing the reality of different perspectives on the rights of people with disability to determine their own priorities and agendas.

The research also identified a number of experiences of poor relationships and at minimum, poor communications and lack of respect for the role of SHOs in PNG. Incidents of exclusion from crucial meetings and expression of the inaccurate idea that people with disabilities can be represented by service providers, were reported by several respondents.

Research respondents noted that they valued support of family and community members for people with disabilities. The emergence of SHOs has sometimes created an emphasis on SHOs seeking resources, in the way of financial donations, land, buildings and equipment. The ways in which these requests are managed within partnerships or funding relationships are likely to have an influence on perceptions about SHOs. The large community event to celebrate the launch of the Henganofi SHO during the research process, illustrated that there was considerable community and local organisational support for the idea of the SHO. A large number of speakers congratulated the SHO's establishment, endorsed the idea of rights of people with

disabilities and encouraged community support. The SHO's future management of funds and resources and ability to work collaboratively to promote the rights of people with disabilities, will influence community perceptions and ongoing support.

Several organisations which collaborate with SHOs, such as the National Disability Resource and Advocacy Centre and Creative Self Help Centre, noted that they contributed to SHOs in the form of training, opportunities for participation in events and transport. This collaboration is valued by SHOs.

#### **4.1.7 Role of Government and relations between SHOs and Government**

The board of PNGADP gave high praise to the support of Dame Carol Kidu, who up until the time of this research process in PNG, was the Minister for Community Development and in that role, played a role as champion for the rights of people with disability. The responsibility for Government services in the disability area rests with the Ministry of Community Development. The issue of the rights of people with disability has entered into the focus of the Department within the last three years. The Government of Papua New Guinea established a Disability and Ageing Section in the Department of Community Development in 2004, but since 2008 has paid much greater attention to disability rights issues. Its recognition of PNGADP as the national umbrella organisation for SHOs and its encouragement for people with disabilities to establish new SHOs across the country has been an important influence on the current situation of SHOs. The Government's recognition is expressed through some government assistance to strengthen the capacity of PNGADP, which at the time of this research, is used to fund the salaries of two of the three staff members.

The Government of PNG developed a National Policy on Disability which was approved by the National Executive Council in April 2008 and officially launched in July 2009. This policy recognises the rights of people with disabilities to organise themselves and represent themselves. The Government plans to revise this policy in 2012. The Department of Community Development has staff to commence implementation of the National Policy and its modest recurrent budget for disability has begun to increase in recent years.

The Government signed the CRPD in 2011 and has expressed an intention to ratify it by the end of 2011<sup>8</sup>.

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<sup>8</sup> This intention may change given a change of Government which occurred during the research team's visit to PNG.

Funding for service delivery outside the capital city of Port Moresby is the responsibility of provincial governments and district authorities. Importantly, most provincial and district budgets do not allocate any ongoing or even one-off funds for disability services or for SHOs. This has significant bearing on the existence and sustainability of SHOs at these levels. The national government recognises the need for a determined policy roll-out and increased consultation between levels of government, since most activity for people with disabilities is required at provincial and district not national levels. At the time of this research, it is not clear how far this national-provincial consultation has progressed, but there are signs, such as in the Henganofi case study (see Annex 3) that provincial administrations are open to supporting SHOs in some form.

Government relations with SHOs vary significantly across PNG, from the national level, where relationships are relatively good, to provincial level, where there are at least a few examples of collaboration, to district level, where there appear to be very limited relationships, apart from the situation in Henganofi where the SHO actually officially commenced during this research process.

#### **4.1.8 Partnerships with others**

Several respondents noted the strong value placed on partnerships between PNG SHOs and external partners. PNGADP has worked collaboratively with organisations outside PNG including PDF, APIDS, PWD Australia, Disabled Peoples International (DPI), Disability Rights Fund (DRF), CBM/Nossal Partnership on Disability Inclusive Development and Asia Pacific Development Centre on Disability (APCD). These organisations have contributed in various ways including providing access to training and funding, as well as policy support and advice. Funding through some of these organisations has been provided through PNGADP to provincial level activities, such as workshops on CRPD in Eastern Highlands in 2010. PNGADP has also coordinated several of its board members and members to participate in Australian Leadership Award Fellowship programs, funded by AusAID, since 2008.

Participation by PNG in Pacific regional disability activities is particularly valued by PNGADP. The Pacific Disability Ministers meeting in PNG in 2012 is regarded as an opportunity to raise the profile of the issue nationally.

#### **4.1.9 Priorities for future of DPOs**

In addition to information generated through meetings and interviews, the research workshop on 3 August provided an opportunity for participants to identify and discuss

their own priorities for developing and strengthening their DPOs. They agreed on the following priorities<sup>9</sup>:

- Empowerment of board members and members through increased understanding about rights and confidence to speak up about them
- Partnerships with others who share a commitment to the rights of people with disabilities (see 4.1.10 below)
- Collection of data about our people with disabilities and their priorities across the country as well as about the services available for them at the moment
- Establishment of a DPO for people who are deaf
- Joint organisation of workshops by DPOs and service providers on how to apply rights based approaches in practice
- Encouragement to provincial DPOs to be established, including lobbying to provincial governments to support them, and support to be accessed by PNGADP from other sources
- Monitoring by PNGADP across the country about activities and information
- Stronger secretariat to manage day-to-day affairs of PNGADP
- Establishment of a fund which would be used to provide DPOs with establishment costs and train emerging leaders in how to build their organisations including attracting people as board members and members, logistical support, equipment, communications and networking

#### **4.1.10 Priorities for partnership support**

Research respondents identified a consistent list of ways in which they sought future support from partners, including:

- training for board members in all aspects of organisational governance, management, financial management and advocacy
- provision of information and skills development in advocacy and awareness raising about rights and how to use rights based approach

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<sup>9</sup> Some participants sought the establishment of a DPO for indigenous people living in Port Moresby, separate from the national capital DPO, but this suggestion was not agreed by all participants.

- funding for communications (phone and computers and internet connections) and transport costs to be able to organize meetings of members and boards and to raise awareness in rural areas
- workers (such as volunteers) to assist organisations in systems, structures, proposal-writing and financial management
- equipment to assist members and to enable organisations to operate
- ongoing moral support on how to address disability inclusion.

## **4.2 Summary**

In summary, apart from a peak of activity in 2002, rapid changes appear to have occurred since 2009 in relation to the capacity of SHOs. Four major factors in the PNG context appear to influence these more recent changes:

- appointment of Ipul Powaseu as the President of PNGADP and an active board of office bearers, who are building on previous achievements of the organisation
- high level of attention to the issue of disability rights by PNG's Minister for Community Development
- development of a comprehensive Strategic Plan for PNGADP which is linked to the Government's Disability Policy and reflects rights based thinking
- initial efforts to implement this Strategic Plan in cooperation with others.

This research did not seek to ascertain perspectives about “absent” capacity in PNG DPOs, but rather to identify perspectives on existing DPO capacity and ways to build upon it in future. While some organisations which partner with DPOs or have dealings with them struggled to identify DPO strengths, others confirmed those listed above. It is clear that some important steps have been taken to build the capacity of DPOs in PNG in recent years. Most people consulted during the research recognised that DPO emergence is recent, promising, challenging and overall, a significant opportunity to improve the lives and status of people with disabilities. Everyone participating in the research was able to identify priorities for future development of DPOs and commented in various ways about their hopes to see the fruits of efforts by people with disabilities themselves and to see the strengthening of collaborative partnerships to support them.

## **5. Lessons learned about the research methodology**

The approach to research includes a commitment to continuous learning, so the research team reflected on what had worked well in PNG and on ways to improve the research process in future. The research team considered that the following elements worked well:

- lots of information was generated in meetings and the workshop
- participation in the workshop was very good (26 members) and it was a particularly useful way for people with disabilities to raise and share ideas, discuss shared objectives and plan ahead
- visits to provincial areas and districts were particularly valuable and interesting
- SHO representatives (board, staff members and members) were able to articulate their visions and experiences in comfortable and supportive meetings and they talked freely and openly
- several people were particularly helpful and cooperative, especially Ian in Madang, Marcel and Don in Goroka
- the security awareness and contacts provided by Richard Mandui were much appreciated

The following suggestions were made:

- more discussion about the budget details should be held prior to the in-country visit – who is to manage, how much is allocated and what can be afforded
- more discussions should be held prior to the in-country visit about decisions about who to meet (perhaps two pre-visit phone conferences are necessary)
- focus group discussions should be more informal, so they are more like conversations (and less Q and A)
- research questions should have been sent in advance
- the research team should stay in countries longer than 7 days to obtain deeper understanding of the complexity of the context

## **Annex 1: List of Research Activities**

### **Wednesday 26 July 2011**

Research Team planning

### **Thursday 27 July 2011**

Meeting with staff of PNGADP

**Team split into two and travelled to Goroka and Madang**

### **Friday 28 July 2011**

**In Goroka:** Meetings with:

- Kepsy Fontenu, Chair and other board members of Henganofi DPO
- Sister Teresia, Mercy Works
- Cecilia Bagore, Lecturer in Teaching Visually Impaired students, Callan National Education Institute
- Marcel Pool, Interim Chair, Eastern Highlands Disability Committee

**In Madang:** Meetings with:

- Mase Warel, Administrator, Creative Self Help Centre
- Desmond Beng, Madang Disabled Self Help Group
- Ian Apeit, Project Coordinator, National Disability Resource and Advocacy Centre
- Richard Gambu, Ability Reliance Centre, Usino Bundi District, Madang

### **Monday 1 August 2011**

Meeting with Mr Karoho Donisi, Chair, Pari Village Self Help Organisation

### **Tuesday 2 August 2011**

Meetings with:

- Red Cross School for the Deaf
- St John School for the Blind
- PNG Blind Union

### **Wednesday 3 August 2011**

Workshop with DPO board members, staff and members (see Annex 2 for workshop outline) = total 26 participants, of which 6 were women

### **Thursday 4 August 2011**

Meeting with Konia Doko, Assistant Secretary, Disability and Elderly Division of the Department for Community Development in PNG

## **Annex 2: Research Workshop Outline**

1. Introductions
2. What is capacity?
3. What is capacity development?
4. Strengths based approaches
5. Discussion about findings of research to date and confirmation of agreed list
6. Planning to continue to strengthen the capacity of DPOs

## Annex 3: Case study of new PNG DPO

*“Empowerment starts within oneself: to develop a strong DPO and achieve change, people with disabilities need to take the first step” (Chairperson, PNGADP)*

In Papua New Guinea, the research team witnessed the celebration to launch a new DPO in the district of Henganofi in Eastern Highlands Province. We heard community leaders tell a crowd of over 200 people about their support and commitment to including people with disabilities in community activities and events. We met the proud new DPO President, Kepsy Fontenu. We listened to him talk passionately to his community and special guests, about his new sense of empowerment and strength as a community leader of people with disabilities. He told us that after 10 years of sitting quietly in his village, he attended a Provincial workshop in early October 2010 which made him realize he had the potential to be a leader. At the end of that month, he attended a Highlands Regional workshop on the Convention of the Rights of Persons with Disabilities. He heard stories of other DPOs in the Province and this inspired him to set up the new DPO in his district. Kepsy did not wait for others to help him: he took the initiative, for example by collecting information about people with disabilities in different areas within the district and motivating others to join him. Kepsy knows he will have the responsibility to empower others with disabilities. He also knows he will be supported through this process by his community, DPO officials and the broader disability network in PNG.

The Henganofi DPO Treasurer, Ruth George, was also presented to the community as a new leader and we heard her talk about her rights to speak out as a woman with a disability. Ruth was inspired by Kepsy to join the new DPO. She told the crowd gathered for the launch: “I don’t want you to call us “those people,” as we are part of you, the community. We don’t want charity. Don’t look at our disabilities, look at our abilities. When you separate and isolate us, you hurt our feelings, so just include us in everything.” The celebration was exciting, energetic, colorful and inclusive, with people of all ages joining in and witnessing the emergence of the Henganofi DPO. The performance of the Braille Boys Band, who recently released their first CD nationally, was particularly inspiring and popular. Their title song called “Don’t look at my disability, look at my ability” was perfect for the occasion.

In 2010, Kepsy had attended a workshop for potential DPO leaders, run by the Eastern Highlands Disability Committee (EDC). Just prior to the launching of the new Henganofi DPO, office bearers and community members participated in a two-day workshop to contribute to their planning and capacity development. The research team took the

opportunity of the launch to interview office bearers of the new DPO as they begin their journey of learning and strengthening their organisation. The team found evidence of an impressive start: a board of elected officials, a 6 month action plan, and the official opening of a Disability Resource Centre nearby, where people with disabilities could have access to training as well as other activities. The new DPO is committed to working in the district and to slowly building its organizational capacity and later will be able to share its experience more broadly including engaging in provincial and national activities.

The Henganofi DPO is not the first to be developed in Eastern Highlands Province: others have existed in Daulo and Kainantu in some form for a while. There is now increasing potential for people with disabilities to lead these and other DPOs in the Province. The vision of the EDC, which itself only started in 2009 in Goroka, is that there will be DPOs in all eight districts and leaders from these DPOs will eventually form a Provincial DPO. In the meantime, EDC is a multi-stakeholder committee, comprising representatives from service providers, development NGOs and emerging district level DPOs. Soon after the EDC was formed and its Constitution was drafted, EDC successfully applied to the Provincial Government to obtain funding. This has been used, among other things, to undertake capacity development workshops for potential leaders, just like Kepsy, at district level. The interim Chair of EDC, Marcel Pool, said “we have to work towards people with disabilities having leadership roles so that they have their own voice in organizations that they manage themselves. Still, once they are a DPO, we envisage they will keep working collaboratively with others such as service providers and NGO partners, as well as the Provincial Government.”

What the research team saw in Eastern Highlands Province may not reflect what is happening in other provinces. However, it is a good example of what can be achieved by an inspired leader in their own community, supported by people with a vision and the skills to empower others.

The research team found that at the national level, the PNG Assembly of Disabled People (PNGADP), which is the national DPO, has a strong strategic plan, is providing opportunities for people with disabilities to attend workshops and meetings to develop their skills, knowledge and confidence, and is networking effectively across the Pacific region and beyond. PNGADP aims to develop a coordinated national structure of DPOs from national to district levels. In this structure, PNGADP would be comprised of provincial representatives from DPOs and then provincial DPOs would be comprised of the leaders of district DPOs, such as people like Kepsy.

In Papua New Guinea, there is clear evidence of a shift from a charity and medical approach to disability, to a rights based approach. This is reflected in the emergence

and strengthening of DPOs at various levels. As the largest country in the region, PNG is extremely complex in terms of the diversity of cultures and government structures. It is also very difficult to travel around and this makes it challenging for people with disabilities to meet together to form and sustain DPOs. However, there is great potential for sharing Kepsy's inspiring story across the country. In August 2011, for example, the Department for Community Development in collaboration with PNGADP will host a workshop for leaders of Provincial DPOs, and Kepsy will share his story and we are confident that he will inspire others. The story of the new Henganofi DPO demonstrates that inspired and visionary leadership, good partners and strong networks are critically important for successful DPOs.