

# Collaboration, communication and information: The Disability Action Plan

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The need to redress the disadvantages experienced by people with disabilities is the focus of significant international treaties, policies and plans, requiring dedicated collaboration, communication and information to achieve their purpose and objectives. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is pre-eminent and is intended to ensure that people with a disability are treated equally under law, have the same rights to participate and access to the same quality of services as everyone in the community. The CRPD vision requires concerted action across governmental and non-governmental organisations (NGOs) working with disabled people's organisations (DPOs). Article 32 of the CRPD focuses on international co-operation, including international development programmes and partnerships. The adoption of the CRPD in 2006 signalled a paradigm shift in the treatment of persons with disabilities from a medical and charity model to a social and rights-based approach. It heralded a new era in global efforts to promote and safeguard the civil, political, social and economic rights of people with disabilities through international co-operation.

## Box 1 Prevalence factors

Around 15 per cent of the world's people live with some form of disability or significant difficulty in functioning in their everyday lives and activities (WHO and World Bank, 2011). This proportion is expected to rise as populations age and acquire chronic health conditions. Disability is a particular problem in developing countries, which are home to nearly 80 per cent of people with disabilities, many of whom live in poverty (ibid.). This reflects a strong and enduring link between disability and poverty: poorer people are at an increased risk of disability because of factors such as inadequate housing and sanitation, unsafe work conditions, and poor access to education and health services; conversely, disabilities often impoverish people and trap them in poverty due to lack of employment, and out-of-pocket health and other expenses required to manage disabilities, exacerbated in the absence of universal health coverage and other social protections. Across all countries and income levels, people with disabilities face multiple forms of disadvantage which limit their access to essential services and participation in community life.

Advancing disability inclusive development has emerged as a priority strategy, as is evident from the outcome document of the High-Level Meeting of the United Nations General Assembly on Disability and Development in 2013. This document stresses the need to ensure that people with disabilities are included in all aspects of development, including the post-2015 agenda. Within Asia and the Pacific, the Incheon Strategy to 'Make the Right Real' has provided the first set of regionally agreed disability-inclusive development targets – similar in structure to the Millennium Development Goals – and has been adopted in the current Asian and Pacific 'Decade on the Rights of Persons with Disabilities' (2013–22) even in countries that are not signatories to, or have not ratified, the CRPD. The Pacific Regional Strategy on Disability 2010–15 provides guidance specifically to Pacific island countries to protect and promote the rights of persons with disabilities, and offers a framework for the co-ordination of development partners, governments and society to build a disability-inclusive Pacific.

## The Disability Action Plan 2014–21

The most recent initiative designed to galvanise concerted action is the Draft WHO Global Disability Action Plan (DAP) 2014–21 (WHO Executive Board, 2014). In the plan, WHO recognises disability as: a) a global public health issue, because people with disabilities face widespread barriers in accessing health services and have a lower health status than people without disabilities; b) a human rights issue, because people with disabilities are often subject to discrimination, prejudice and violence because of their disability; and c) a development issue, because disability disproportionately affects poorer people (DAP 3). The DAP is now in its final form following consultations on previous drafts. It is scheduled to go before the World Health Assembly for endorsement on 24 May 2014. Aiming to improve the health, functioning and well-being of people with disabilities (DAP 5), it has the following three objectives (DAP 12):

- (1) To remove barriers and improve access to health services and programmes (where the focus is on improving health outcomes for persons with disabilities)
- (2) To strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community-based rehabilitation (where the focus is on improving activities and participation by persons with disabilities)

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- (3) To strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services (where the focus is on improving understanding of barriers, progress and effective ways to achieve the other objectives)

Drawing on the World Report on Disability (WHO and World Bank, 2011), which provides the broad body of evidence needed for international understanding and action, the DAP recognises that disability ‘cuts across many sectors and involves diverse actors’ (DAP 19). Achieving the objectives of the DAP will require collaboration, communication and information on many fronts and by many actors, including government agencies, NGOs and service providers, development agencies and researchers as well as people with disabilities, and their families and communities. The DAP specifically allocates responsibilities for actions to achieve its three objectives to member states, WHO secretariat, and national and international partners. Active involvement and participation of people with disabilities through their representative organisations (DPOs), in the formulation and implementation of policies and programmes that directly affect their lives, is critical (DAP 16).

Also in line with the world report, the DAP recognises that good quality information and data are essential for deepening the understanding of disability issues, and for providing the basis for policies and programmes to ensure people with disabilities can ‘contribute to society on an equal basis’ (DAP 43). Thus, methodologies for improving information and collecting internationally comparable data on disability need to be developed using uniform definitions based on the International Classification of Functioning, Disability and Health (ICF; DAP 46). The ICF defines

disability in terms of impairments, activities and participation – a multidimensional experience influenced not only by related health conditions but also by a wide range of environmental factors. The ICF provides the common language and building blocks to define, describe and gather information and data on the complex experiences of people with disabilities. Such data is essential to illuminate the correspondingly complex domains of policy, research and statistics in diverse regional and country contexts.

This article illustrates some of the key themes of the DAP, with examples of the variety of activities in Pacific Islands Countries which are already being undertaken and will contribute to meeting the objectives of the DAP.

## Initiatives in the Pacific

In order to achieve the aims of the DAP, many activities involving multiple stakeholders working at different levels and across different sectors are required. The following examples of such initiatives in the Pacific, involving the co-authors, illustrate the breadth of activity now occurring and are indicative of what more is required. The collaboration, communication and information development required by the DAP are exemplified by the power of collaboration among DPOs, government and regional organisations; the value of broad and ongoing collaboration on information development; and the analytical and political efforts that are required to begin to overcome workforce shortages in health and rehabilitation.

## When collaboration and communication need further work

In 2012, WHO Western Pacific Region commissioned the University of Sydney to prepare a discussion paper on an initial exploration of the rehabilitation workforce in member countries of the Pacific Island Forum. The analysis included a desk review of the literature, a survey about rehabilitation workforce in the region based on the International Standard Classification of Occupations, key informant interviews and a workshop.

The study found that there is a significant shortage of rehabilitation health workers in the Pacific region.<sup>1</sup> Despite this, key informants were able to describe good services that people have invested time, energy and commitment into developing. One clear theme that emerged during analysis, however, was that there was little contact between community level services and those services offered in hospital settings for people with disabilities. Key informants in each country described difficulties with the referral pathways, from health services to the rehabilitation services, that are available within health care systems and in the community, such as those provided by an NGO or a DPO.

Effective access to rehabilitation services within a hospital setting depends on a co-ordinated referral system that works through the community unit level to whichever organisational level provides hospital-based rehabilitation, such as provincial or national capital level. According to key informants, barriers to achieving this include a lack of understanding in doctors and nurses about disability and the need for rehabilitation; very few community-based rehabilitation services; and lack of formalised cross-sectoral collaboration between health services and community-based

### Box 2 Kiribati

#### Ratification of the CRPD

The secretariat of the Pacific Community’s Regional Rights Resource Team works with the Kiribati Ministry of Internal and Social Affairs and the national DPO, Te Toa Matoi, in providing training on human rights and disabilities. The collaboration is in response to the ministry’s wish to ensure adequate consultation with the public, as well as with persons with disabilities, on the proposed adoption of the CRPD. The first training programme was undertaken 16–18 September 2013 and was attended by government representatives from the ministries of internal and social affairs, education, health, labour, foreign affairs and environment as well as the Department of Police, National Audit Office and University of the South Pacific, in addition to leaders of DPOs. One of the outcomes of the initial meeting was the development of a draft cabinet paper which recommended that the government consider ratification of the CRPD. The second workshop took place on 19 September 2013 and involved traditional chiefs and community leaders, who endorsed the outcome statements of the first consultation. All participants appreciated the opportunity to have their voices heard by their government and to have their concerns and issues raised onward, through to the United Nations. Following these expressions of support, the Cabinet of the Government of Kiribati showed their endorsement through the ratification of the convention on 27 September 2013.

providers. Inequitable access to rehabilitation services, lack of funding, and prioritisation of rehabilitation and assistive aides were also nominated as problems that require attention.

### Improving information from CBR monitoring

A regional collaboration has resulted in the development of a prototype monitoring toolkit for community-based rehabilitation (CBR) and similar programmes. The toolkit's goal is to improve the quality of information and understanding of such programmes, and to enable programme planning and monitoring based on local priorities and needs. Research and development has occurred over three years (2011–14) and involved collaboration by researchers at the University of Sydney and representatives from government ministries, NGOs, DPOs and service providers in South East Asia and the Pacific islands.

## Box 3 Solomon Islands

### Empowerment through collaboration

A faith-based organisation in the Solomon Islands worked with the Ministry of Health, community-based rehabilitation (CBR) section, to enhance life opportunities for adults with disabilities. A training course was devised collaboratively to provide basic life skills training for people with disabilities who had not had the opportunity to go to school nor in most cases to move outside of their immediate environment in their lifetimes. There have now been eight intakes of trainees aged 17 to 52. The training courses are being further developed; where they were initially of six weeks duration, they have now extended to six months. People with physical disabilities have been empowered to become advocates in their own communities. The collaboration is strong and ongoing.

### Collaboration on employment

A training programme and curriculum for disability-inclusive tourism and hospitality has been developed collaboratively by the Ministry of Education and Human Resources Development, together with People with Disabilities of the Solomon Islands. The aim is to enhance employment opportunities for people with disabilities in the hospitality industry. A tourism and hospitality inclusive disability curriculum and programme are currently being developed; a Curriculum Advisory Committee will test them before approval.

### Information for service and workforce planning

The Ministry of Health and Medical Services, through the national community-based rehabilitation (CBR) office in the Solomon Islands, conducted a national disability survey from which it gained information about the number of people with disabilities and the services that people with disabilities accessed. They combined this data with information on the number of CBR workers in the nation and identified a shortage of such workers. This information fed into the ministry's strategic plans. A new training programme for CBR workers was then developed and delivered (by the then Solomon Islands College of Higher Education, now Solomon Islands National University), resulting in 12 new graduate CBR fieldworkers in 2013. Another 23 students are currently doing the same training and are expected to graduate in December 2014.

The collaboration is motivated by two factors: 1) the current state of the field: CBR is a valued approach to achieving empowerment for people with disability as well as their families and communities, but there is a lack of evidence of its efficacy (WHO and World Bank 2011, and more recently confirmed in DAP 21); and 2) the philosophy of the approach: so as to build evidence based on international standards and consistent with the CBR focus on empowerment, the appropriate starting point is to encourage monitoring that is locally owned and controlled (rather than externally imposed), and empowering stakeholders with information to inform programme planning and improvement.

Literature reviews established the need for more consistent monitoring and evaluation tools (Lukersmith et al., 2013) as well as the relevance of the International Classification of Functioning, Disability and Health (ICF) for monitoring and evaluating CBR – especially the participation and environmental dimensions (Madden et al., 2013a). The reviews also captured other types of information not included in the ICF but considered important and relevant for monitoring CBR.

Workshops with collaborators developed and refined ways of establishing local information priorities among stakeholders, and identified priority information needs (see methods in e.g. Madden et al., 2013b; WHO, 2013). They also established the form of the toolkit, which consists of a menu from which CBR managers and stakeholders can select information items for monitoring purposes, and an accompanying manual with practical guidance on the use of the menu, including instructions on how to decide information needs, and create a monitoring system to suit the information needs and circumstances of different programmes and communities.

Based on this work, enabled by funded workshops and continued via electronic means (email, online discussion group, Skype), a prototype manual and menu is scheduled to be freely available for testing or use from May 2014.<sup>2</sup>

### Collaboration improves and unifies information

An NGO in Papua New Guinea (PNG) redesigned its registration form for people with disabilities participating in its organisation. It used ideas from collaborative workshops and the CBR monitoring menu (as it was in 2013) to draft a new form. The University of Sydney team was asked to comment and the NGO made further changes in response; they also adapted and worded items to suit the local community and environment. The form resulting from all this work contained:

- Items designed locally (e.g. information about guardianship arrangements)
- Items on the need for help with activities; the list of activities was selected from the ICF (now in the CBR monitoring menu)
- Precise language (e.g. talking about impairment of parts of the body, rather than disability in parts of the body)
- A new question about the person's interests and goals

There is now wider interest in the registration form in PNG, with a national statistics organisation suggesting other NGOs consider using it, with local adaptation as needed.

### Information sharing, national measurements

A team at the University of Sydney, Australia, is undertaking exploratory work, in collaboration with others working in the disability field, towards a new integrative measure of disability and functioning. Measurement of functioning in the 21st century often involves a complex set of relationships among people and systems. One response to this complexity is to offer a large number of context-specific measurement instruments – specific to health condition, treatment or policy area, and setting or health profession. Another approach, particularly relevant for large national programmes, is to seek or work towards an integrative measure, relevant to many different health conditions, professions, and treatment and support settings. There are several motivations for taking an integrated approach.

First, there is a general drive towards ‘integrative’ and ‘person-centred’ policies and services across both health and disability fields in Australia and internationally. Modern health systems recognise the importance of human functioning in addition to diagnosis and disease prevention, and that functioning is a core concern of the disability field. Information about functioning is important in the context of chronic disease, mental health, healthy development and ageing, and the rights of people with disabilities to participate and function in all areas of life (Madden et al., 2012a; 2012b). The inclusion of people with disabilities in mainstream services – now known, for example, as disability-inclusive health or inclusive education – is recognised as requiring special attention. Measurement tools which are relevant across service settings and time are therefore needed.

There is also the problem of how multiple, context-specific measures affect the people whose functioning is being measured and act as barriers to a more comprehensive understanding of their situation. The use of different measures, across different but related programmes and across a variety of settings, can be a problem for the person involved if each new service and setting requires new measurements, or uses differing (although possibly related) concepts about functioning. There is a further risk related to the lack of suitable generic instruments for use in and across programmes and service settings: that pre-existing measurement tools may be used without careful evaluation of whether they are ‘fit for purpose’.

Finally and importantly, there has been limited use made of the ‘common language’ for functioning and disability – the ICF (WHO 2001) – to create new generic tools attuned to current disability and health philosophies, policies and national programmes (Cerniauskaite et al., 2011). The use of the ICF to underpin such information infrastructure is in line with in the Global Disability Action Plan.

### Multi-stakeholder movement

The CDRP, the World Report on Disability, the Global Disability Action Plan, the regional strategies and the ICF together provide an invaluable and coherent suite of resources for policy and action on disability.

The path forward, as set out in the DAP, requires the involvement of many stakeholders: people working at all levels of government; people with disabilities and their organisations (DPOs); and service providers (both government and NGOs), families, professionals and

researchers. Multi-stakeholder and multi-sector involvement is necessitated by the complex and dynamic nature of the disability experience and the variability of the circumstances in which people live. Collaboration and communication are needed to develop sound, agreed and sustainable solutions to the problems that exist – and to act on them. Taking health services as an example, it might require community health services, hospital based services, DPOs and professionals to work together to ensure people with disabilities get equal access to the services they need. Improving and using consistent information about disability is an essential part of planning the actions that are needed and of evaluating progress. Collaboration, communication and information are, then, three of the key ingredients for success in meeting the objectives of the Disability Action Plan.

### Concluding remarks: Workforce issues and knowledge networks

Workforce shortages of highly trained professionals were identified as a worldwide problem in the World Report on Disability (WHO and World Bank 2011). Analysing information from multiple sources, on disability in the population and services available, identified unmet needs and enabled decisions to be made in the Solomon Islands to expand the CBR workforce. The broader challenges that lie ahead in the Pacific were reported in a WHO-commissioned report on the rehabilitation workforce. Shortages of community-based rehabilitation services were apparent. Common threads through many of the system problems identified were inadequacies in time, resources and sometimes also willingness to collaborate, communicate and provide easily accessible information.

Collaboration between service providers, DPOs and university researchers is an essential element in starting work on overcoming the lack of integrative cross-sectoral disability measures that are suitable for use in national programmes, which adhere to the key international policies of the CRPD and the standard information frameworks of the ICF.

Opportunities and means for collaboration and communication have been created by the formation of strong DPOs, supported in turn by the existence of strong regional networks such as the Pacific Disability Forum, which is the peak regional body that works in partnership with DPOs in the region. The support of funders (including governments and NGOs in the region) for collaborative activities involving multi-sectoral partners has also been a critical ingredient in several of the examples.

Low-cost electronic communication was another significant enabling factor for several of the examples presented – in the form of email and online discussion spaces as well as Skype, Viber and similar facilities. The availability of such means makes it possible to maintain and strengthen links made in person, and continue work over the life of projects.

The examples outlined in this article provide ‘windows’ on Pacific region activities – activities that relate directly to all the main objectives of the Global Disability Action Plan. They illustrate the importance of unifying frameworks, and of regional networks and mechanisms. Collaboration and communication are strong linking threads: they are equally important for policy development, service and workforce development, and information development.

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## Endnotes

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- 2 Available at: <http://sydney.edu.au/health-sciences/cdrp/> [Accessed 22 April 2014].

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