

# Understanding disability support systems in the Pacific

## Executive Summary

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## **Disclaimer**

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*This publication has been funded by the Australian Government through the Department of Foreign Affairs and Trade. The views expressed are the authors' alone and are not necessarily the views of the Australian Government.*

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## Background

Disability support services and systems are essential for promoting the independence, dignity, wellbeing, and equal participation of people with disability. Recognised as a key precondition to inclusion under the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the Pacific Disability Forum's Preconditions for Inclusion Framework, disability support services are a priority to ensure equity for people with disability and crucial for achieving the Sustainable Development Goals (SDGs).<sup>1,2,3</sup> However, frameworks and definitions of disability support services and systems for low- and middle-income countries have been lacking, making it challenging to set priorities, advocate effectively, and drive change.<sup>4</sup>

In the Pacific, family members are the key providers of support for people with disability, however, a better understanding is needed of the broader systems of support for both people with disability and their families. Strengthening this understanding is essential to inform contextually-relevant responses that improve access to support, and promote equity and wellbeing.

## Purpose

The Pacific Disability Forum has called for a shared understanding of disability support services for the Pacific. This study responds to that call by exploring existing supports and gaps for people with disability and their families, and proposing a framework to guide advocacy, policy and action on disability supports tailored to Pacific Island countries.

It is anticipated that the study outputs may be used by any individual or organisation with an interest in understanding or progressing disability support services for people in Pacific Island countries. This may include Pacific organisations of people with disability (OPDs), governments, donors, implementing agencies, and others to support planning, implementation of, and advocacy for, disability support services.

## Methods

Funded by the Australian Government's Department of Foreign Affairs and Trade (DFAT), the study was a collaboration between the Nossal Institute, CBM Australia, the Pacific Disability Forum, Fiji Disabled Persons Federation, and Fusi Alofa Association Tuvalu. Methods included a literature review of existing evidence, stakeholder workshops and in-depth interviews with people with disability, support persons and select stakeholders in Fiji and Tuvalu. These settings were selected on the advice of the Pacific Disability Forum to provide evidence from diverse Pacific contexts at different stages of progress in terms of disability inclusive development and the availability of disability supports.

## Findings

### Literature review

A review of peer-reviewed and grey literature revealed despite widespread ratification of the UNCRPD across Pacific Island countries, there remains a lack of evidence on the nature, availability, and effectiveness of disability supports and support services in the region. Academic and grey literature on disability supports is limited and often context-specific, making it difficult to draw regional conclusions or inform scalable policy. Whilst existing evidence indicates that most support is provided by family there is

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<sup>1</sup> United Nations, *Convention on the Rights of Persons with Disabilities*, United Nations (New York, 2006), <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-articles>.

<sup>2</sup> United Nations, *Transformation of services for persons with disabilities. Report of the Special Rapporteur on the rights of persons with disabilities*, United Nations (New York, 2023), <https://www.ohchr.org/en/documents/thematic-reports/ahrc5232-transformation-services-persons-disabilities>

<sup>3</sup> Pacific Disability Forum, *Pacific Disability Forum Preconditions Issues Papers: Complete Series* (2024), <https://pacificdisability.org/wp-content/uploads/2024/12/Introduction-to-Precondition-Framework-Issues-Paper.pdf>.

<sup>4</sup> Xanthe Hunt et al., "Community Support for Persons with Disabilities in Low- and Middle-Income Countries: A Scoping Review," *International Journal of Environmental Research and Public Health* 19, no. 14 (2022–07–06 2022), <https://doi.org/10.3390/ijerph19148269>.

little in the way of evaluation to understand the benefits, challenges and gaps. There is also a notable absence of research on community-based mechanisms, extended family roles, and culturally embedded support practices that align with the UNCRPD. This underscores the urgent need for research to document current practices, support needs, and culturally appropriate rights-based models of support.

Compounding these evidence gaps is the lack of clear definitions, policy direction, and conceptual frameworks for disability support services that are culturally and contextually relevant in the Pacific. While the Pacific Disability Forum's Preconditions for Inclusion framework provides the signpost, there is no overarching guidance for development of support services in the Pacific.<sup>5</sup>

### **Qualitative study**

Findings from stakeholder workshops and in-depth interviews in Fiji and Tuvalu indicated that:

- People with disability need and utilise supports across all areas of life to contribute meaningfully to their families, households, and communities. Key areas where support is needed include personal care, domestic household chores, accessing education, working to earn income, and participating in community, religious and sporting activities.
- Inaccessible environments, including lack of accessible transport, housing, and negative attitudes, increase the need for support and impact individuals' autonomy and independence.
- The main supports used were personal support from family members or others, to use assistive technology, and making changes to their environment or how activities are performed.
- Family members are the preferred and trusted source of supports.
- Family members are the main source of supports for daily activities. Although there were examples of men providing supports, these roles were mostly provided by women. Provision of support has opportunity costs for family members in terms of lost education and income generation, and limiting community participation.
- Migration patterns, both overseas and rural-urban, and changing household structures away from traditional multi-generational households are impacting the availability of family support.
- Supports provided by services and organisations are scarce and mostly located in urban areas. Training, regulation and retention of a support workforce is an ongoing challenge.
- There is a need for greater support for family members who provide caregiving and support. Some families are utilising paid in-home support to assist with caregiving or provide respite, and some highlighted a need for more information on how to provide supports well.
- Existing community mechanisms of mutual care and support in Pacific Island countries present an opportunity that can be harnessed to support people with disability and their families in the communities in which they live.
- Social protection for people with disability is available but insufficient to meet the costs associated with daily support needs.
- Disaster preparedness and response that is more disability inclusive was raised as a key issue in light of increasing natural hazards and the impact of climate change. Evacuation and access to emergency provisions were highlighted as key support needs during emergencies.

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<sup>5</sup> Pacific Disability Forum, *Pacific Disability Forum Preconditions Issues Papers: Complete Series*.

## Outputs

Findings from the literature review supports PDF's call for a shared Pacific understanding of disability support services that is grounded in evidence, is strengths-based, and designed to do-no-harm. Findings from the qualitative study provide evidence of the current situation of disability supports in Fiji and Tuvalu and important contextual factors that must be considered when advocating for, planning and implementing disability support services in Pacific Island contexts.

Drawing on the findings are two key documents intended to facilitate understanding of support services and systems, the local contextual factors impacting access and availability of support for people with disability, and to assist in identifying priorities for action.

1. A Framework for Understanding Disability Support Systems in the Pacific (including tools for contextual analysis and priority setting)
2. Stories of People with Disability and their Support Persons

Using these documents to progress support services and systems for people with disability will help to bridge family support with supports provided by services and organisations, promote inclusion and agency of people with disability, reduce reliance on institutional care, while reinforcing the Pacific's cultural traditions of mutual support and community assistance.

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