



Tuvalu Study on People with Disability

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Key Definitions Relating to Disability¹

Accessibility	Accessibility describes the degree to which an environment, service or product allows access by as many people as possible, in particular people with disabilities.
Assistive devices or assistive technology	Any device designed, made or adapted to help a person perform a particular task. Products may be specially produced or generally available for people with a disability.
Barriers	Barriers are factors in a person's environment that, through their absence or presence, limit functioning and create disability – for example, inaccessible physical environments, a lack of appropriate assistive technology, and negative attitudes towards disability.
Disability discrimination	Any distinction, exclusion or restriction on the basis of disability that has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise on an equal basis with other, of all human rights and fundamental freedoms; includes denial of reasonable accommodation.
Inclusive schools	Children with disabilities attend regular classes with their age-appropriate peers, learn the curriculum to the extent feasible, and are provided with additional resources and support depending on need.
Inclusive society	One that freely accommodates any person with disabilities without restriction or limitation.
Special schools	Schools that provide specialised services for children with disabilities and remain separate from broader educational institutions. Also called segregated schools

¹ These are universally accepted definitions and are from the *World Report on Disability*, 2011

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This study has been the product of cooperation between many parties, all of whom were vital to the process and end product.

The Government of Australia through the Pacific Women Shaping Pacific Development (*Pacific Women*) program provided the financial means to undertake this study, without which it could not have taken place.

The Government of Tuvalu have endorsed this study and through the Ministry of Home Affairs and the Gender Affairs Department provided essential support to the study throughout its duration.

The board, staff, members and volunteers of the Fusi Alofa Association (FAA), the disabled people's organisation in Tuvalu, played a key role in the study from its initial inception.

The short-term technical adviser for the study Helen Tavola ably led the study team.

The country focal point of the Secretariat of the Pacific Community's Regional Rights Resource Team, Ms Eseta Lauti, translated the research instruments, provided interpretation at the fieldworker training and offered essential support to the study.

The fieldworkers endured difficult conditions to travel to all of the islands of Tuvalu and they did so voluntarily. Their hard work and persistence made this study happen. The fieldworkers were:

- Eseta Lauti (SPC / RRRT)
- Maho Homasi (Ministry of Home Affairs)
- Alice Are (FAA)
- Lusiesi Tautai (FAA)
- Sepola Paulo (FAA)
- Molomolo Tauaisi (FAA)
- Taupaka Utinilau (FAA)

Kim Robertson, Adviser – Gender Statistics, Secretariat of the Pacific Community, provided invaluable support with data collation, analysis and development of tables.

Kulene Kulene was the study coordinator in Tuvalu and ensured that logistical operations ran smoothly.

People with disabilities in Tuvalu and their caregivers opened their homes and their hearts to the fieldworkers and openly shared their stories. A key objective of the study is that it improves support for people with disabilities in Tuvalu, so their participation was critical. This study is for them.

Executive Summary

In 2013, the Australian Department of Foreign Affairs and Trade (DFAT) in consultation with the Government of Tuvalu (GOT), non-governmental agencies and communities, formulated the Tuvalu *Pacific Women* Country Plan (2015–2018). The country plan was subsequently endorsed by the GOT in 2015. The country plan outlined the Australian Government's commitment to spend up to \$1.8million over three years (2015–2018) on initiatives that support gender equality in Tuvalu.

One of the key activities identified in the Tuvalu *Pacific Women* Country Plan (2015–2018) is to support the Tuvalu Disabled Persons Organisation, Fusi Alofa Association of Tuvalu (FAA) and the Ministry of Home Affairs to conduct a disability study. The intention of the study was to collect information about the experiences of persons with disability (PWD) and their carers. It was to create a holistic picture of the challenges experienced in their everyday life. Specific questions asked were:

- How many PWD are there in Tuvalu and what are the barriers they face in accessing services?
- What are the current support mechanisms for PWD and how successful are they at providing support to PWD?
- What are appropriate actions or interventions that can be put in place to improve support for PWD in Tuvalu?²

Pacific Women contracted a short-term technical adviser who trained a team of seven fieldworkers to conduct fieldwork in the nine islands of Tuvalu from March to May 2017. The main research instrument was a questionnaire for people with disabilities. *Kaupule*³ members, teachers, nurses and caregivers were also interviewed.

The questionnaire for PWD used the six screening questions known internationally as the Washington Group Short Set of Disability Questions to determine whether the person being interviewed had a disability. Known persons with disabilities as well as persons over 60 years of age were targeted for the research.

The study identified and interviewed 466 PWD in the nine islands of Tuvalu. This is 4.5 per cent of the population, based on the Tuvalu National Statistics Office end-2016 estimate of 10,156.⁴ The most common disability was difficulty with mobility, followed by sight, memory, self-care, communication and hearing. Many people have more than one disability. There was a predominance in the older age group, with 58.5 per cent being 61 years of age or older; 32 per cent between 21 and 60 years of age; and 9.2 per cent were 20 years of age or younger. There were more women than men, due largely to the longer life expectancy of women. The most common cause of disability was perceived to be old age, followed by almost equal numbers of disability present since birth; accidents and as a result of diseases.

The study found that people with disabilities in Tuvalu face multiple barriers that prevent their full participation in life. Almost half said that their disability prevented them from participating in family and community events, largely due to physical barriers. Health facilities were inaccessible to around half of the participants. Stigma, discrimination and abuse towards PWD are widespread in Tuvalu. People with psychosocial disabilities are the least well understood and have the fewest services available to them. People living in the outside of Funafuti feel that they have fewer services for PWD in every regard. The study found overall a great need for assistive devices, which can enable PWD to participate more fully in their communities and to live their lives with dignity.

² The Terms of Reference for the Study are at Annex 1

³ The *kaupule* is the island council on each island. A quarterly assembly is held by each *kaupule* where the annual budget and development plans are prepared by the island council.

⁴ Details of sex and island of residence are in Table 1

The study found that just over 20 per cent of PWD live in circumstances of hardship.⁵ It also found that people with severe disabilities and psychosocial disabilities face additional barriers as do their caregivers.

Disability, gender inequality, and discrimination are closely interlinked. Women experience disability differently in that they are more likely than men to have a disability in their lifetime, due largely to their longer life expectancy. Women with disabilities are subject to all forms of abuse, teasing, bullying, harassment, including sexual abuse. Women with disability were twice as likely to live in hardship compared to men with disability. The majority of caregivers are women, who often have little outside support.

Although the Department of Education has positive intentions to develop and implement policies to address inclusive education, the study concludes that children with disabilities are not well served by the education sector. Children attend school, but most do not receive any specialised attention and are left behind, leaving school with inadequate levels of education.

The health system provides free basic health care to all the people of Tuvalu but as a small island developing country, it is unable to provide much needed specialist care especially for those with psychosocial disabilities.

Around three-quarters of PWD in the study had caregivers, of whom all but three were family members. The study interviewed 97 caregivers, 78 per cent of whom were women, and identified their main needs and challenges as: financial needs; psychiatric and other specialist medical care; education and training; assistive devices and rehabilitation. Caregivers reported cases of bullying, abuse and discrimination of the PWD in their care. There is no formal support for caregivers.

PWD themselves find the main challenge is lack of finances to support themselves well. They also feel that there is a lack of understanding of the rights of PWD.

The study makes these recommendations to improve the lives of PWD in Tuvalu⁶:

Recommendation 1. National disability policy: the draft disability policy needs to be revised and streamlined to be achievable. It should then be adopted as a priority matter for all stakeholders to adhere to and follow. The Ministry of Home Affairs is the custodian of the policy and should monitor and coordinate its progress.

Recommendation 2. National policy on hardship: the proposed national policy on hardship being developed by the Ministry of Home Affairs should address PWD living in hardship as a priority area. A further investigation into PWD, especially women with disabilities, living in hardship should be included in the activities under the policy. The Community Affairs Department of the Ministry of Home Affairs and faith-based organisations should endeavour to visit and provide support to the PWD identified in this study as living in hardship, as they are the most vulnerable people in society.

Recommendation 3. Constitutional review: the Constitution of Tuvalu is under review and disability should be included as a grounds for discrimination.

Recommendation 4. Laws: the laws of Tuvalu need to be reviewed and aligned to the Convention of the Rights of Persons with Disabilities (CRPD), as per the GOT's obligations under the CRPD.

⁵ As explained fully in the Report, the assessments of hardship were made (subjectively) by the fieldworkers based on agreed indicators including size of dwelling and living space for the PWD; hygiene and sanitation; ease of movement in and around the house; and general adequacy of standard of living.

⁶ The Recommendations section of the Report are aligned to the relevant Articles of the Convention on the Rights of Persons with Disabilities and identifies potential partners.

Recommendation 5. Fusi Alofa Association (FAA): needs the support of all parties as it plays a vital role representing the voice of PWD. The GOT should continue to provide financial and technical support through:

- The Ministry of Home Affairs as the focal point and coordinating Ministry for disability for the GOT; which is also charged with the Disability Benefit Scheme; and for providing a grant to FAA;
- The Department of Education to support the education of children with disabilities; and
- The Ministry of Health should enter into Memorandum of Understanding with FAA with to work together on the coordination of provision of assistive devices, medication and rehabilitation.

FAA also needs to take the following actions.

- Continue to strengthen its advocacy and awareness programs on the rights of PWD, including conducting training and radio broadcasts, in order to improve negative attitudes towards PWD. There is a particular need for this in the outer islands.
- Seek outside assistance to develop sign language teaching and learning in Tuvalu.
- Seek funds to reactivate its affiliates on the outer islands as they are currently largely inactive.
- Develop wheel-chair repair capability.
- Provide training in independent living for youth and adults with disabilities.

Recommendation 6. Education: the Department of Education (DOE) can improve educational opportunities for children with disabilities to build an inclusive society for all by doing the following.

- Fully implement Tuvalu Education Strategic Plan III; finalise Inclusive Education Framework and implement it.
- Employ teachers trained in inclusive and special education appropriately and consistently.
- Encourage more teachers to train in inclusive education.
- Provide in-service training on inclusive education to existing teachers, including training on identification of children with disabilities.
- Implement the proposal to include human rights education in schools, so that children understand that all people have rights and that teasing, bullying, abuse and discrimination are not acceptable.
- Work closely with FAA to improve the FAA school, which could eventually become a resource centre for inclusive education. A trained Inclusive Education teacher should be appointed to the FAA school by the DOE with appropriate resource allocations.
- Children attending the FAA school should be able to travel on the school bus, with a caregiver if necessary.
- Seek teachers of special and inclusive education from the Fiji Volunteer Teachers Scheme.

Recommendation 7. Health: while it is fully recognised that a small country cannot provide the specialist medical personnel of a large country, there are many opportunities to better use visiting specialist teams. There is an urgent need for psychiatric care in particular.

- Every effort should be made to make such specialist care available to PWD in the outer islands by bringing them to Funafuti for consultations.
- In-service training on disabilities should be provided to health personnel.
- Rehabilitation services should be increased.
- Work with FAA as in Recommendation 5 on a coordinated approach to procuring and distributing assistive devices and other medical services.

Recommendation 8. Caregivers: three-quarters of the caregivers of PWD are women as this is typically seen as part of their caring or nurturing role. While seeing it as a 'labour of love', many caregivers are worn out by the constant demands of caregiving. While families are the primary caregivers, there needs to be a backstop service for caregivers that could provide support through the following services:

- provide basic training in the care of PWD, including correct lifting;
- facilitate the acquisition of assistive devices;
- provide respite care when necessary; and
- provide a link between health providers and caregivers.

Conclusions

This study provides a comprehensive picture of the lives of PWD in Tuvalu and the challenges they and their caregivers face. While there are no easy or instant solutions, there are many areas of policy and practice that can be improved, in order to improve the lives of PWD.

Disability impacts women in many different ways. There are more women with disabilities compared to men; they are more likely to be subject to teasing, bullying and abuse; and they are more likely to live in situations of hardship than men. Women are the main caregivers of PWD and face many challenges in this role.

Clearly, PWD face barriers in many areas of their lives and these barriers prevent their full participation and inclusion in society. The study makes recommendations that can reduce the barriers and enhance the dignity and enjoyment of life for PWD in Tuvalu.

A positive factor in the disability scenario in Tuvalu is the high level of family support, with only seven PWD living alone. All caregivers in the study were family members. Just over half of study participants reported receiving some form of assistance from churches, women's, youth and community groups.

Despite high levels of family support and care, the study revealed alarming levels of stigmatisation, bullying and abuse, all of which undermine the dignity of disabled people and which are apparently deemed to be acceptable by society at large.

As a party to the CRPD, the fundamental concepts of respect for inherent dignity and autonomy of persons with disabilities, non-discrimination, participation, inclusion, equality, and accessibility need to be addressed. As the GOT continues to implement the CRPD, it must create an enabling environment so that PWD are empowered to participate and are more fully included so that they can contribute fully to the life of their nation.