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Tuvalu Study on People with Disability

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Abbreviations and Acronyms

CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
DFAT	(Australian) Department of Foreign Affairs and Trade
DOE	Department of Education
FAA	Fusi Alofa Association
GOT	Government of Tuvalu
MOH	Ministry of Health
NCD	Non-communicable diseases
PMH	Princess Margaret Hospital
PWD	Persons / people with disabilities
SPC / RRRT	Secretariat of the Pacific Community’s Regional Rights Resource Team
STA	Short-term adviser
TESP	Tuvalu Education Sector Plan
TuFHA	Tuvalu Family Health Association

Key Definitions Relating to Disability[1]

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 or 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

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[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 four and a half 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.

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[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 Tuvalu[6]:

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.

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:

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[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.

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 (IE) 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 IE 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.

1 Introduction

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.

The objectives of the study are to:

- Collect data and information on PWD in Tuvalu to assist key stakeholders in developing baseline information for their reporting under the Convention of the Rights of Persons with Disabilities (CRPD);
- Identify the barriers that are faced by PWD and their caregivers in accessing services in Tuvalu as well as the social and attitudinal barriers they face;
- Assess the capacity of existing outer island disability committees and/or organisations in supporting the needs of PWD and their caregivers; and
- Identify relevant strategies to improve support for PWD in Tuvalu.

Specific questions to be answered by the study are:

- 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?[7]

2 Methodology

The *Pacific Women* Support Unit contracted a short-term technical adviser (STA) / consultant, Dr Helen Tavola, to guide and oversee the process. Dr Tavola worked in collaboration with members of FAA, the Gender Affairs Department of the Office of the Prime Minister and the Community Affairs Department of the Ministry of Home Affairs.

The approach of the study is a human rights based approach, guided by the CRPD which Tuvalu has ratified. The CRPD definition of disability is:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (CPRD Article 1)

Disability is a human rights issue because people with disabilities experience inequalities, for example in education; and people with disabilities are subject to violations of dignity, for example when they are subjected to violence, abuse, prejudice or disrespect due to their disability.[8] The human rights based approach differs from earlier approaches to disability in that it looks at the rights of PWD to participate fully in society. The earlier commonly-used medical approach saw disability as an

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[7] The Terms of Reference for the Study are at Annex 1

[8] World Health Organisation and The World Bank, *World Report on Disability*, 9, 2011, Geneva

impairment of individuals that needed rectifying or normalising. A charity approach was common for a long time and still pervades today, sees PWD as objects of pity who need to be helped. The social model of disability maintains that disability is caused by the way society is organised, rather than by a person's impairment or difference. It looks at ways of removing barriers that restrict life choices for disabled people.

The reality is that there is a fusion or spectrum of approaches evident in any society, including Tuvalu. Medical practitioners typically take a medical stance whereas disability advocates opt for a human rights based approach.

The design of the study was aided by background documentary research which was supplemented by the consultant's meetings with stakeholders in Tuvalu.

Fusi Alofa nominated five people to be trained as fieldworkers for the study, comprising the teacher for the FAA school, two members and two volunteers. In addition, a staff member from the Community Affairs Department of the Ministry of Home Affairs and the country focal officer for the Secretariat of the Pacific Community's Regional Rights Resource (SPC / RRRT) joined the fieldwork team and took the roles of lead fieldworkers to provide leadership. The FAA teacher was also the lead fieldworker on one island trip.

The consultant designed the research instruments in consultation with all partners and conducted training for the fieldworkers in March 2017. Due to the potentially sensitive nature of some questions, considerable emphasis was placed on ethical and confidentiality issues and how fieldworkers should deal with such issues, which indeed did arise during the study.[9] The main survey instrument, a questionnaire for PWD, was piloted in Funafuti and slight revisions were made to the responses and to coding. Following the training, fieldwork started in Funafuti. Three trips with different teams of fieldworkers covered the islands of Tuvalu.[10] These were:

- Trip 1: Nukulaelae and Niulakita
- Trip 2: Vaitupu, Nukufetau and Nui
- Trip 3: Nanumaga, Niutao and Nanumea

The *kaupule* on each island was informed prior to the visits and radio announcements and programs explaining the purpose of the study were made to inform people of the purpose of the study, encouraging their cooperation and participation.

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. This set of questions is based on everyday functioning and is widely considered to be the most robust way to collect internationally comparable data on disability. These questions, shown below, focus on functioning in six domains and do not attempt to label disabilities.

Table 1 Questions about functionality

	No	Some	A lot	Unable
Do you have difficulty seeing, even if wearing glasses?	1	2	3	4
Do you have difficulty hearing, even if using a hearing aid	1	2	3	4
Do you have difficulty walking or climbing steps?	1	2	3	4
Do you have difficulty remembering or concentrating?	1	2	3	4
Do you have difficulty with self-care such as washing all over or dressing?	1	2	3	4

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[9] Such issues were largely those of abuse and extreme hardship.
[10] A map of Tuvalu is at Annex 3

	No	Some	A lot	Unable
Because of a physical, mental, or emotional health condition, do you have difficulty communicating, (for example understanding or being understood by others)?	1	2	3	4

If a person answered that they had difficulty in any one of the domains above, the interviewer proceeded with the full interview.[11] This set of questions was effective as an introductory screening device. In three interviews, the answer was no to all of the questions, indicating no disability, yet the interviewee identified himself or herself as disabled. One case was a person with curvature of the spine (kyphosis). This person was able in all of the domains above, but had faced a significant amount of stigma and discrimination that had a profoundly negative impact on his life, so was included in the study. In another case, the person had no problem with sight but one of her eyes is always watery / teary. The distress caused by this condition profoundly affected many aspects of her life and was a disabling condition. Another was a person with clubfoot (talipes), which had affected his life greatly. These three people thus were included in the study.

The preferred respondent to the questionnaire was the PWD herself or himself. However in cases where the PWD was too young, too infirm, had communication difficulties or was unable to answer for other reasons, their caregiver responded. In some cases, the PWD and the caregiver both answered questions. In total, 338 PWD responded to the questions themselves; in 78 cases the questions were answered by a caregiver; and in 50 cases, both the PWD and caregiver responded.

Responses to the Washington Group questions are necessarily subjective: peoples' perceptions of their abilities and are not medical diagnoses or a substitute for such. It is therefore not possible to say, for example, how many people had specific disabilities such as autism, cerebral palsy or who had had a stroke or amputation, although fieldworkers were encouraged to write explanatory notes on the questionnaire. Since many disabilities, especially those in the psychosocial domain are never formally diagnosed, this approach, which is used world-wide, is preferable to labelling people. The overall view in this study is that people tend to understate their disabilities rather than overstate them.

The interview schedule contained 70 questions covering age and age of onset of disability; living circumstances; education; access to services; participation in family, community, political and sporting activities; use of assistive devices; needs for support; experiences of discrimination; views on improving the lives of PWD in Tuvalu; and hardship.

A short questionnaire for caregivers was administered where appropriate. This focussed on issues and challenges facing caregivers and the support they need.

Questions were also asked of *kaupule* members, teachers and nurses on different islands regarding PWD on their respective islands.

Due to time and resource constraints, the study was not able to visit every household in Tuvalu. The sampling was purposive in that it focussed on households where there was a known PWD or person over 60 years old. The study deliberately included those over 60 years of age as internationally it is evident that many disabilities occur in that age-group.

More than 46 per cent of older persons – those aged 60 years and over—have disabilities and looking ahead, the global trends in ageing populations and the higher risk of disability in older people are likely to lead to further increases in the population affected by disability.[12]

The questionnaires were translated into Tuvaluan and fieldworkers had the option of using either an English or Tuvaluan version. Most chose the latter. The lead fieldworkers then translated answers into English.

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[11] Sixteen people interviewed responded that they had no difficulties in the screening questions so were not included in the final count.

[12] https://www.un.org/development/desa/disabilities/disability-and-ageing.html

The draft report was presented to a wide range of stakeholders, including GOT Ministries and Departments and civil society organisations, in Tuvalu on 12 July 2017. There was discussion around the proposed recommendations, which has been incorporated into the Report and recommendations. Several of those present provided written feedback following the consultation.

2.1 Challenges and constraints

The study faced numerous challenges and constraints. It was initially envisaged that the FAA would play a key role in this study and would take charge of organising all logistics for the fieldwork. However, at the time the study took place, FAA was undergoing considerable change as its Office Manager left the organisation and it lacked the capacity to fulfil that role. Staff from the Gender Affairs Department of the Office of the Prime Minister filled in until a study coordinator was appointed half way through the study period.

Travel to the outer islands had to be re-scheduled several times. The initial plan was to join the Police on their boat for two trips, but after the first trip, the Police boat needed urgent and major repairs. The Manaui was chartered from the Fisheries Department and the plan was to visit all six remaining islands in one trip. Bad weather forced an early return to Funafuti and it was over a week before the final trip commence. Such events are risks that were considered in the planning for the study.

The fieldworkers found that in some islands, there was not enough time to visit all households with over-60s, so they concentrated on known PWDs that had been identified by the *kaupule*, teachers and/or nurses. This factor was clearly a limiting factor in the comprehensiveness of the study.

The fieldworkers were all volunteers apart from the lead fieldworkers who were already in salaried jobs. They were paid daily subsistence allowances to cover meals and transport but were not paid for their time.

Despite the challenges, the required tasks were completed and a credible number of PWD were interviewed in order to draw useful conclusions.

3 Background to Disability In Tuvalu

The 2012 Tuvalu National Census identified 198 PWD of the population who were under 60 years of age, which was 1.83 per cent of the total population of 10,780. However this was a slightly higher proportion – 2 per cent – of the under 60 age group who were questioned. In that Census, the interviewers were instructed to read out the CRPD definition of disability. They then asked the question: 'Is there any member of this household who falls under this definition and is 60 years and under?' [13] [14]

The United Nations Development Program (UNDP) in association with GOT and New Zealand Aid Program developed profiles of several islands in 2011/2012. This study concluded that there were around 430 PWD in Tuvalu.[15] While this provides a rough estimate, it does not answer questions relating to barriers that PWD face; their access to services; issues faced by care-givers.

The different representations of the frequency of disability in the 2012 Census and the 2012 UNDP report highlight the difficulties and complexities in measuring disability in a population. The World Report on Disability discusses this issue extensively and states: 'The question design and reporting source can affect estimates'.[16] The current trend is to move from an 'impairment approach', to a

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[13] Tuvalu national census questionnaire final draft, 2012, Question H55

[14] It should be noted that the proposed mini-census for late 2017 will use the Washington Short Set of Disability Questions to identify disabilities (as was used in this Study) which may produce quite a different result.

[15] It is not clear how the UNDP studies identified disabilities.

[16] WHO and World Bank, *World Report on Disability*, 2013, 23

‘difficulty in functioning approach’ using the Washington Group Short Set of Disability Questions that was used in this study.

Some disability studies exclude certain age groups, as with the 2012 Tuvalu Census, which excluded those over 60 years of age. Most common though is to exclude those under 18 years of age. The World Report on Disability cites the figure that the average frequency of disability from 59 countries (some 650 million people) was 15.6 per cent of those aged 18 and over.[17] The current Tuvalu study does not exclude any age group so the proportion would be expected to be considerably lower than 15 per cent, as most disabilities occur in older age groups.

3.1 National policy on disability

There has been a draft national policy on disability since 2013 and consultations on it have taken place on several islands. The draft policy is wide-ranging across a number of sectors. It is anticipated that the policy will be finalised and endorsed in 2017.

The policy will apply to different stakeholders including Government Departments and Ministries including primarily Health, Education and Home Affairs. Some sections will particularly apply to the non-governmental organisation Fusi Alofa.

The Ministry of Home Affairs is the focal point for disability in the GOT. The Attorney General’s Office is charged with ensuring that human rights obligations are met and reported on in a timely manner.

3.2 The legal and human rights context

The Constitution of Tuvalu has a statement on rights influenced by the Universal Declaration on Human Rights but disability is not acknowledged as a grounds for discrimination. The US Country Reports on Human Rights Practices for Tuvalu (2015) reported that:

The law does not specifically prohibit discrimination against persons with physical, sensory, intellectual, or mental disabilities, including in employment, education, air travel and other transport, or the provision of other state services. Government services to address the specific needs of persons with disabilities were very limited. There were no mandated building accessibility provisions for persons with disabilities. The one multi-story government building had non-operational elevators, and there were no elevators in other multi-story buildings. Persons with disabilities had limited access to information and communications.

The GOT ratified the Convention on the Rights of Persons with Disabilities (CRPD) in 2013. This signalled a significant commitment on the part of the Government to address the rights and needs of PWD across many different areas. One of the obligations under the CRPD is to align national legislation to be compliant with the CRPD. To date this has not been achieved but there are intentions to undertake this process.

The GOT has also ratified the Convention on the Rights of the Child (CRC) and the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW). Both CRC and CEDAW have cross-cutting issues in common with the CRPD. The Concluding Observations to the CRC in 2013 included a section on children with disabilities, with several recommendations relating to inclusive education, early intervention and legal protection. The Concluding Observations on CEDAW in 2015 called for data to be disaggregated by disability.

The Report of the Special Rapporteur on the Human Right to Safe Drinking Water and Sanitation in 2012 addressed concerns of vulnerable people and households, in that they were treated the same

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[17] Op cit, 27

as others, with no special consideration. This implies that vulnerable people (of all types, including PWD) were not singled out but regarded the same as the whole population.

Tuvalu participates in the Universal Periodic Review process and in its second report, FAA presented a shadow report. FAA also reported to the CRC Committee in 2011.

In January 2017, a National Human Rights Action Plan was launched by the Prime Minister, Enele Sopoaga, which aims to enshrine human rights in the country's development priorities. Mr Sopoaga said the plan was the outcome of consultations with government departments, non-governmental organisations and communities to identify human rights priorities. In the Forward to the Action Plan he stated that:

Our development priorities will assist the marginalised, the old and the young, our men, women and children, our people with disabilities and all those who call Tuvalu home. It is in realising our most basic and fundamental rights that we realise our basic dignity and worth as human beings.[18]

The Action Plan notes that human rights and culture are not opposing concepts but mutually reinforcing in that they promote the entitlements and privileges of all Tuvaluans to live a life that protects their humanity and dignity.[19] In the context of this study on disability, humanity and dignity are particularly pertinent concepts.

3.3 Service provision for PWD in Tuvalu – benefits

It is generally acknowledged that there has been increasing awareness of the issue of disability and the needs of persons with disability (PWD) in recent years, due largely to the advocacy of FAA. The Community Affairs Department in the Ministry of Home Affairs and Rural Development is responsible overall for protecting the rights of persons with disabilities.

In 2015, the GOT started its disability support scheme. Initially there were only six recipients as the criteria were very strict: those born with a disability or bedridden were the only ones entitled to support. In 2016, the GOT broadened the criteria and as of March 2017, there were 86 people receiving the disability benefit. Each application needs to be endorsed by a doctor who sits on the assessment committee. The disability benefit is only payable up to 70 years of age, when it converts to the Tuvaluan senior citizens support scheme that started in 2009. Recipients cannot receive both benefits, which are both $70 a month. The *kaupule* in Nanumea supplements benefits with an additional $30 a month.

The introduction of the disability support scheme was a significant move into social protection by the GOT as it signalled both Government’s sense of responsibility for vulnerable members of the community and a move from the commonly accepted view that looking after disabled and elderly family members is solely the role of the family.

3.4 Education

Tuvalu’s Education Strategic Plan II 2011–2015 considered the education of children with disabilities by including Inclusive Education in its outcomes. Despite Tuvalu’s education policy specifically supporting the provision of special education as well as inclusive education, the inclusion of all children with disabilities in school has not been fully realised. The lack of trained teachers for children with special needs, the poor infrastructure of school facilities and the inaccessibility of schools are mentioned as main reasons why the education system in Tuvalu has not been ready to provide inclusive education as set out in their plans and policies.

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[18] Government of Tuvalu, *Tuvalu Human Rights National Action Plan 2016 – 2020*, 2017, iv
[19] Government of Tuvalu, *Tuvalu Human Rights National Action Plan 2016 – 2020*, 2017, 1

The Tuvalu Education Strategic Plan (TESP) III 2016–2020 has disability inclusiveness as a cross-cutting issue. Outcome 1 of the TESP is:

> All young people in Tuvalu from ECCE to secondary and post-secondary that includes children with special needs, have physical access to an education provider that is relevant and worthwhile.[20]

The TESPIII also includes the development of an Inclusive Education Framework and plans for all schools to be accessible. These intentions are reiterated in the Tuvalu Human Rights Action Plan.

The Tuvalu Education Sector Situation Analysis 2016 noted that:

> Special needs children are mostly not included in mainstream schooling with some attending the FAA community centre on Funafuti … The capabilities of the schools to deal with most special needs children is an issue and the Education Department is taking steps to remedy this but it will take time. TESP II identified inclusive education and as such the Department will endeavour to support all schools and the FAA community centre to provide the best available education for all.

While the Department of Education theoretically keeps records of children with disabilities, staff admit that there is a lack of skills to diagnose disabilities and no systematic records are kept. They are generally more aware of learning problems rather than physical disabilities but also lack the skills to address learning difficulties.

There was formerly a teacher trained in special education at Nauti Primary School on Funafuti who identified around 15 children with disabilities who were in a separate class. That teacher has now left Nauti. The current head-teacher at Nauti told the study that they now send children with disabilities to the FAA school.

This informal referral system does an injustice to the children concerned, especially since the FAA school has been closed for most of 2017 due to water problems. It does not provide transport, whereas Nauti does, and it does not have any fully-trained teachers.[21]

Some students with disabilities attend government-run public primary schools both in Funafuti and in several outer islands. Tolise Primary School on Vaitupu started a program in 2016 of enrolling a small number of children with special needs. This was driven by a teacher and head-teacher who were both trained in this area. During this study, teachers in several islands identified children who had learning difficulties who attended their schools.

The FAA started a separate school for children with disabilities in Funafuti in 2011. In 2017, it had 17 students, enrolled, nine girls and eight boys, with an age range from two to 22 years, with five or six attending on a regular basis. Children have to find their own transport which is a deterrent to regular attendance. Most of the children have intellectual disabilities or have developmental delays. The school is open for three days a week and on the other days, the teacher does home visits to children and the elderly. The only full-time teacher reported that there is a low level of parental support.

Some children who had been attending the FAA school attempted to be mainstreamed into Nauti Primary School but for various reasons, including bullying and teasing, the children returned to FAA.

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[20] Tuvalu Education Sector Plan (TESP) III 2016–2020, p17

[21] The FAA teacher is a trained Early Childhood teacher and has done a six-month certificate in disability studies with the Australia Pacific Technical College. While she is very competent, she is not recognised as a primary school teacher. The teacher is supported by volunteers.

The FAA school is not registered with the Department of Education, which in fact regards it as a centre and not a school as it does not meet the requirements of a school. The Department does however give an annual grant of $5,000 which goes towards the salary of the teacher.

Department of Education officials acknowledge informally that more could be done to strengthen the FAA school by, for example, providing professional development opportunities and increasing funding. These have yet to be realised.

Despite these positive moves, there is a general lack of learning opportunities for children and young people with disabilities, especially in the outer islands.[22]

3.5 Health

Tuvalu has one hospital, the Princess Margaret Hospital (PMH), located on Funafuti. The PMH provides primary and secondary care services for patients from Funafuti and those referred from the outer rural islands, where there are clinics staffed by nurses who provide primary care and preventive services. Patients needing clinical care that cannot be offered at the PMH are referred to overseas hospitals mainly in Fiji, New Zealand and India, through the Tuvalu Medical Treatment Scheme. Health services are provided by the public sector as there is no private health sector and are free of charge to citizens of Tuvalu. [23] This scheme is an important part of the curative health services and takes around a third of the health budget. If, however, a person elects to seek treatment overseas and is not referred by the Ministry of Health (MOH), they must self-fund their treatment.

Given the small population of Tuvalu and its limited human resources, it is impossible to provide a full range of specialist services on a permanent or full-time basis. There is currently a resident surgeon and an anaesthetist on long-term contracts and other medical specialists visit the country to provide services. Some, such as the obstetrician / gynaecologist visit regularly while others visit on an ad hoc basis.

The MOH indicated that a psychiatrist visits twice annually from either Taiwan or Tonga. Most assistance in the area of mental health focuses on depression. While most people with mental health issues are cared for by families, some are admitted to hospital. If they are aggressive, they are sent to prison. There are no long-term patients with mental health issues in the hospital.

The MOH has paramedical staff including a physiotherapist, pharmacist, radiologist, laboratory technician, dentist and biomedical technician. The physiotherapist works mainly at the hospital and occasionally visits outer islands. His main area of attention is musculoskeletal and sports physiotherapy; followed by cardio respiratory physiotherapy and neurology (stroke rehabilitation). In the 2015 MOH Annual Report, the physiotherapist noted that when he is on duty travel such as attending a course or workshop provided by development partners, there are no services available. There is no Community Based Rehabilitation in Tuvalu.

The MOH does not keep specific data on the current health care needs of persons with disabilities in Tuvalu.

Health centres on all islands have standardised procedures for checking patients and newborn babies are routinely checked for issues such as *talipes* and cleft palate. Some of these cases are sent overseas for operating as they cannot be addressed in Tuvalu. Some children with cerebral palsy require physiotherapy which may be provided in Tuvalu or else the patient is sent overseas.

The most common surgical procedure in Tuvalu is amputation, due mainly to complications from diabetes or hypertension. In 2016, there were 23 amputations and to July 2017, there had been nine

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[22] Tuvalu Education Sector Situation Analysis 2016, p22

[23] Much of the information in this section is from the *Ministry of Health Annual Report, 2015*, which was the most recent available.

amputations. Strokes are also common, also as a result of non-communicable diseases (NCDs). Visiting overseas surgeons operate on cataracts. Some young eye patients are referred to Fiji.

The provision of assistive devices is a major challenge. The MOH works with FAA in the provision of assistive devices such as wheelchairs and crutches, all of which are donated from overseas. Spectacles are also donated from overseas but all of these donations are on an ad hoc basis. Virtually nothing is done to help those with hearing impairments. The physiotherapist noted in the 2015 MOH Annual Report that there were challenges with the high demand for walking aids and assistive devices, working within a limited allocated budget that was unable to meet the demand from clients. There were also problems with the duration for procurement of orders and for supplies to arrive. There is also an issue matching donated equipment including assistive devices with the needs and demands of the Tuvalu population including PWD.

NCDs such as diabetes, hypertension and stroke are a major burden on the health system as well as being a significant cause of disability, especially in the elderly. The Tuvalu National Strategic Plan on NCDs (2011–2015) stated that:

> Preliminary results from baseline STEPS Survey in 2006 indicated high levels of obesity (75.2 per cent), smoking (33.4 per cent), binge alcohol drinking (21.8 per cent) and low levels of physical activity (55.3 per cent) among the adult population (25-64 years). Prevalence of diabetes and hypertension among the adult population (25–64 years) were 29.5 per cent and 32.9 per cent respectively, which have increased by three folds as seen over the last thirty years.

In 2015, the MOH reported that the leading causes of death were NCDs: Diabetes Mellitus Type 2; cardiac arrest; hypertension; septicaemia; and stroke.[24] The MOH is making a concerted efforts at health and nutrition education in order to improve well-being but the high dependence on imported foodstuff contributes to a complex situation.

The Tuvalu Family Health Association (TuFHA) works in the area of sexual and reproductive health rights with a clinic in Funafuti and outreach clinics. It does not target PWD but services are open to them. TuFHA is aware that it could do more in the disability area and is seeking support from its regional body to do this.

3.6 Fusi Alofa Association

Fusi Alofa Association (FAA) is a non-governmental organisation for people with disabilities, established on 15 May 2009, in the capital, Funafuti. It is the first and is still the only one of its kind in the country, with the main aim of advocating for and improving the lives of people living with disabilities in Tuvalu.

The organisation has a membership of more than 60 people with different disabilities. It is governed by a Board, 75 per cent of whom are PWD. It rents an office space in Funafuti, and until March 2017 the office was managed and run by one paid staff, whose salary was paid by the Pacific Disability Forum.[25] FAA receives an annual grant of AU$25,000 from the GOT (Ministry of Home Affairs) and a further AU$5,000 from the Department of Education for the school.

FAA has a strategic plan with the following objectives:

- To promote and advocate the rights of persons with disabilities in Tuvalu stipulated in the CRPD even more so, the domestication of that Convention.
- To advocate for full participation in the national planning and decision-making processes in all climate change related issues as well as the individual island disaster preparedness plans.

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[24] MOH Annual Report 2015, 7

[25] Fusi Alofa Strategic Plan 2016–2018, p6

- To strengthen and develop the capacity of ALL Fusi Alofa members including women and youth with Disabilities to be sustainable and self- reliant.
- To strengthen disability inclusive development partnership with Government, CSOs, development partners and donor agencies. Secure the necessary funding with these partnerships to maintain current professional services and facilities as well as sustain growth in line with the FAA strategy.
- To provide specialised education services for children with disabilities in Tuvalu.
- To strengthen the governance and operation of Fusi Alofa.[26]

FAA has affiliate member organisations on four other islands of Tuvalu: Nanumea, Nui, Nukulaelae and Niutao. These disabled persons' organisations operate independently from FAA. The fieldwork for this study found that most of these are currently inactive.

Prior to the establishment of FAA, the Tuvalu Red Cross Society was the main voice on disability issues and it had a disability program. In the Tuvalu case, this meant that carers and service provision dominated the work and discussions rather than PWD themselves. Tuvalu Red Cross Society facilitated the development of FAA Tuvalu and has continued to support the DPO since its establishment in 2009.

The Tuvalu Red Cross now sees disability as a cross-cutting issue across all of its work and it advocates for the inclusion of PWD, especially in disaster preparedness plans. The Red Cross works closely with FAA as it does not want to duplicate activities.[27]

3.7 Findings of the study

This study report is structured around the major research questions stated above. The report provides both quantitative and qualitative data. Where gender is a significant variable, data is disaggregated by sex. In some cases, the main body of the report contains summary data and more detailed data is provided in the annexes.

4 How Many PWD are there in Tuvalu?

The study identified and interviewed 466 PWD in all 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. A summary of the numbers by island is in Table 2 below. This compares to 198 of people under 60 years of age identified by the 2012 census that required people to respond to the CRPD definition of disability. It should be noted however, that this study was not as comprehensive as a national census, as not every household was able to be visited due to limitations of time and resources. Thus the total number of PWD in Tuvalu is likely to be slightly higher than 466, which is not presented as a definitive number. The mini-census, scheduled for late 2017, plans to use the same Washington Short Set of Disability Questions to identify PWD as this Study, and it may yield a higher number as it will inevitably be more comprehensive. The 2017 census count of PWD will include all people, not just those over 60 as with the 2012 census.

Table 2 Summary of numbers of PWD interviewed in the study, by island

	Men	Women	Total
Nanumea	20	10	30
Nanumaga	5	15	20
Niutao	7	18	25

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[26] Fusi Alofa Strategic Plan 2016–2018, p5

[27] Interview with Soopanga Saufatu, General Secretary of Tuvalu Red Cross

	Men	Women	Total
Nui	15	22	37
Vaitupu	25	36	61
Nukufetau	12	15	27
Funafuti	106	149	255
Nukulaelae	4	6	10
Niulakita	1		1
Total	**195**	**271**	**466**

As would be expected, the frequency of disabilities generally aligns with the population of various islands. Table 3 shows a summary of disabilities nationally. Detailed tables with types and degrees of disability by island is at Annex 2. This data is based on the Washington Group questions discussed earlier.

Table 3 Summary of disabilities nationally

Domain of difficulty	N	%
Sight	286	21
Hearing	145	11
Mobility	324	24
Remembering	237	17
Self-care	185	14
Communication	177	13
Total	**1,354**	**100**

The most common disability is difficulty with mobility, followed by sight, memory, self-care, communication and hearing. The number of disabilities recorded overall is much higher than the number of those interviewed because many PWD recorded more than one disability. The average number of disabilities per PWD is shown in Table 4.

Table 4 Average number of disabilities

Island	Men	Women	Total
Nanumea	3.1	2.5	2.9
Nanumaga	3.4	3.7	3.6
Niutao	2.1	2.9	2.7
Nui	3.1	2.9	3.0
Vaitupu	2.6	2.9	2.8
Nukufetau	2.3	2.4	2.3
Funafuti	2.7	3.1	3.0
Nukulaelae	2.0	3.0	2.6
Niulakita	4.0		4.0
Total	**2.8**	**3.0**	**2.9**

The ages of PWD in the study varied from birth to over 80 years of age as shown in Table 5.

Table 5 Current ages of PWD in study

Age group	Men	Women	Total
0-5	4	4	8
6-10	11	3	14
11-15	8	4	12
16–20	4	5	9
21–25	10	6	16
26-30	11	7	18
31-35	6	4	10
35-40	8	6	14
41-45	8	7	15
46-50	6	9	15
51-55	8	9	17
56-60	17	28	45
61-65	33	49	82
66-70	31	51	82
71-75	13	27	40
76-80	8	24	32
80+	9	27	36
Not stated		1	1
Total	195	271	466

Table 5 shows that there are more women with disability compared to men: 58 per cent of those interviewed were women and 42 per cent were men. One reason for this is that women live longer than men and Table 5 shows that there are more women in the 60 and over age category.[28] This finding concurs with the global situation where there are more women than men with disability: Global prevalence is greater for women than men, standing at 19 per cent compared with 12 per cent respectively.[29]

Table 5 also shows a predominance of disabilities in the older age groups. 58.5 per cent of all PWD in the study were 61 years of age or older; 32.1 per cent were in the 21-60 age group that loosely corresponds with the working population; and 9.2 per cent were in the 0–20-year-old age group.

Older persons – those 60 years of age and above – are disproportionately represented in disability populations across the world. Globally, populations are ageing and Tuvalu is no exception. This is due to various factors including outward migration, which is primarily of people in the working age group; lower birth rates resulting in fewer young people; improved health systems meaning that people live longer. The high level of NCDs is a contributing factor in the high level of disabilities among older age groups.

The age of onset of disability is significant as those who were born with disabilities have substantially fewer opportunities in life compared to those who develop disabilities later in life. People with disabilities from birth are less likely to have received education, been in employment, married or had

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[28] The MOH estimates that in 2015 the life expectancy was 61.7 for men and 65.1 for women. (This shows a significant reduction compared to the SPC estimate for in 2010: where the life expectancy for men was 67.4 and for women 71.9. (MOH Annual Report 2015 and www.spc.int)

[29] http://www.unwomen.org/en/digital-library/publications/2017/6/issue-brief-making-the-sdgs-count-for-women-and-girls-with-disabilities?subject=http://www.unwomen.org/en/digital-library/publications/2017/6/issue-brief-making-the-sdgs-count-for-women-and-girls-with-disabilities

families. Thus in terms of life chances, the PWD in the study fell into three broad categories: those who were born with disabilities from birth to 20 years of age; those who acquired disabilities as young people often due to accidents; and age-related disabilities, often the result of NCDs. Table 6 shows the frequencies of age of onset of disability

Table 6 All persons with any difficulty across one or more of the 6 domains

Age at onset of disability	Persons with a disability		
	Men	Women	Total
From birth	43	34	77
0–20	25	21	46
21-60	65	98	163
61+	55	103	158
Don’t know	7	15	22
Total	**195**	**271**	**466**

Note: a table with detailed ages of onset of disabilities by island is at Annex 2.

Study participants were asked what they thought were the cause of their disabilities. Their answers were their own opinions and are shown in Table 7.

Table 7 Cause of disability

	Men	Women	Total
From birth	43	34	77
Accident	32	47	79
Disease (e.g. diabetes, stroke)	31	48	79
Old age	49	96	145
Curse / punishment	1		1
Unknown cause	24	26	50
Side effect of medication	5	6	11
Other – explain[30]	10	12	22
Not stated		2	2
Total	**195**	**271**	**466**

Old age was by far the most commonly perceived cause with 32 per cent of all cases. This shows that people generally think that some degree of disability is a normal part of the ageing process.

The study also sought to find out how many PWD had albinism or epilepsy. Three cases of albinism and 41 cases of epilepsy were recorded.

5 Barriers Faced by PWD

PWD face barriers to their participation in different aspects of life in different ways. There may be physical barriers especially for those with mobility impairments. Barriers can also be the attitudes of others towards PWD when they participate. The opposite of a barrier is an enabling factor, thus for

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[30] Other reasons included various illnesses including leprosy, pneumonia, gout, asthma, arthritis, measles; inherited disability; caused by substance abuse including alcohol, smoking, methylated spirits or drugs; perfume sprayed in eyes; failure of traditional treatments; black magic; too much swimming in sea; affected by smoke from cooking fire; violence; electric shock; laziness; too much hard work; fishing; strained eyes making handicraft.

example, assistive devices can be an enabling factor to living a full life but the lack of devices is a barrier.

5.1 Participation in society

Participation refers to the level of involvement in social life, which is an important part of functioning in society. Participants in the study were asked questions on their levels of participation in family gatherings; family decision-making; church, village and community events; leisure and sports activities; and politics at any level. Table 8 shows the responses given.

Table 8 Participation levels

	None	Some	A lot	Unable	Total
Family gatherings	90	108	230	38	**466**
Family decision- making	166	53	198	49	**466**
Church	113	71	238	44	**466**
Village community events	157	61	188	60	**466**
Sport	260	69	39	95	**463**
Politics	338	10	43	75	**466**

While participation varied across different areas, at least half of all PWD frequently participate in church and family gatherings. When asked whether their disability prevented them from participating, 237 (42 per cent) said that it did while 166 (28 per cent) said that it did not and 58 (17 per cent) said that it sometimes did. (There were 5 not stated). For those who said that their disability prevented participation, physical barriers were the main reason (46 per cent); shame or stigma (17 per cent); communication difficulties was the reason for 11 per cent; other reasons accounted for 24 per cent of non-participation. The other category was mainly due to old age or severity of disability.

The study was informed that attitudes towards disability are shaped by both cultural and religious beliefs and that these attitudes discouraged participation. There used to be a notion of abnormality associated with disability and that those who were not perfect should not participate in church as they had been cursed by God. The main EKT Church in Tuvalu is now challenging this attitude and is proactively attempting to change mind-sets.[31]

Some PWD do not participate at all in any areas of life, indicated in Table 8 by those who answered ‘No’. While it may be understandable that many PWD may not participate in politics or sports, almost 20 per cent of PWD do not participate in family gatherings; 35 per cent do not participate in family decision-making; 24 per cent do not participate in church; and 33 per cent do not participate in village community events. The inability to participate in community life can affect PWD negatively. The example below shows how an amputation prevents a PWD from participating. It also shows how this issue is interlinked with accessibility and hardship.

> A woman who had an amputation a year ago due to diabetes is not able to attend any family, community or church activities due to her disability. Everything is inaccessible, including her home. She has a wheelchair but it is in poor condition. The fieldworker reported that her house was very filthy and had a foul smell. Her home was in a poor state and needed repairs and maintenance.

In some cases, PWD are isolated and not given the opportunity to participates, as in this example:

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[31] From background Interviews with key informants for this Study and from the consultation on the draft policy on 12 July 2017

> A woman in her 20s who has been disabled since birth. She has low vision and cannot walk, talk or remember. She is epileptic and is bedridden. She is isolated in her room and does not participate in any family activity. She has never been given the chance to socialise. She is totally dependent on others for her basic needs and care.

Participation is increasingly used as an important measure of functioning in disability studies. When a person is unable to participate for any reason, they are often marginalised and excluded. In an inclusive society, efforts are made to ensure the participation of all people.

5.2 Accessibility

Participants were also asked about accessibility to their home environment; school; hospital; church; shops; community facilities and transport including by road and sea. The lack of accessibility is a barrier.

Table 9 Accessibility

	Accessible	Inaccessible	Not stated/ NA	Total
Home	334	131	1	**466**
School	40	101	141	**282**
Hospital / health centre	227	239		**466**
Church	240	225	1	**466**
Shops	190	276		**466**
Community facilities	198	266	2	**466**
Transport	206	258	2	**466**

The main difficulty with accessibility by far was physical barriers such as transport or difficult buildings (198 cases) followed by a smaller number of cases of shame or stigma or communication difficulties (35 each). Other reasons were mostly due to the severity of disabilities or old age.

5.3 Stigma, discrimination and abuse

Stigma and discrimination is widespread as is bullying and abuse and these are barriers to the participation of PWD in society. Study participants were asked whether they had experienced bullying or abuse and 85 PWD (18 per cent of participants) responded positively. People with psychosocial disabilities and very visible disabilities experience the worst cases. In many cases, the teasing was based on physical appearances, resulting in the PWD concerned isolating themselves and choosing not to attend school or participate in their community, in order to avoid such abuse. The PWD concerned feel that they are 'looked down upon'. Some PWD reported verbal and physical abuse by relatives and caregivers, which is never reported to authorities.

Children are particularly sensitive to bullying in school due to their disabilities. Sometimes this means that their education is interrupted. Some examples are: [32]

- Child with clubfoot, needs special shoes and physiotherapy; is teased by other children including cousins about his clubfoot.
- Child with hearing impairment said, 'before the teachers knew about my disability they would get angry at me, but now they understand my situation'.

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[32] Names are not used in examples and case studies to protect the identities and confidentiality of the PWD. In most cases, the examples are quoted verbatim.

- A boy with mental disabilities from birth is bullied by other boys at times. His mother said, 'people tend to understand physical disabilities more because they can see it, not so much for mental disabilities'.
- A woman 44 years of age was born deaf. She completed primary school but chose not to go to secondary school. She has never had the chance to learn sign language or have a hearing aid but has developed a kind of sign language that her family understands. She has never married or had children.
- A five year-old girl, deaf since birth with severe communication problems, attends primary school where other children tease her. She lives in a deprived home environment, in a house in poor condition with no income earner in the family.

The long-term effects of being rejected by the school system are shown in this example:

> A 21 year-old man has a hearing impairment since childhood due to meningitis, which causes communication difficulties. He said, '(I)n Class 2 my teacher told my mother I need not come to school anymore because I was distracting the other pupils'. He would love to do other training but as he did not finish primary school, most courses are not accessible to him. His mother said: 'When my son goes out, people, often his peers, would tease him and say mean things to him. This upsets him and he comes home angry. When he is in this state, the only thing we can do is ask the police to take care of him in prison until he cools down. Stigma and discrimination are still practiced on my island. This makes me very sad and depressed'.

This young man is totally dependent on his parents to take care of all his needs. Most of his rights have already been violated.

Several cases of abuse including sexual abuse were reported to the study. This included at least two cases of rape, in one case by a relative. These cases have not been elaborated upon in order to avoid identifying the individuals concerned. Disabled men are also subject to sexual abuse and at least one case was reported to the study.

Discrimination can also be a subtle deprivation of rights, such as in this case:

> A man in his 60s who was born deaf said, 'I feel that I have not fully enjoyed my birth rights as a man because of my disability, so my sisters get to make some major decisions concerning our family lands etc. without seeking my views'.

Many people are apparently unaware of their casual discrimination against PWD, while using negative language such as joking about Fusi Alofa and labelling people as 'Fusi Alofa' meaning disabled and subtly excluding PWD from community events. As a key informant to this study stated, '(T)here is still a long way to go to disability inclusiveness in Tuvalu'.

5.4 People with psychosocial disabilities

Psychosocial disabilities are the least understood type of disability. Within this category, there is a range of types, including those who were born with psychosocial disabilities, those who developed different forms of mental illness later in life and cases of dementia in the older population.

There is minimal assistance, medical or otherwise, for people with psychosocial disabilities and none reported being on medication, although numerous caregivers noted that they badly needed medical care to prescribe some form of tranquilising or calming medication. The solution for those who become uncontrollable or violent is to send them to prison. Some caregivers said that they had no alternative but to call the police and ask for their loved ones to be locked up until they calmed down.

Many caregivers feel that they lack moral or personal support and there are no counselling services available.

Most people who have had psychosocial disabilities since birth had not attended school, due largely to their parents' decisions, although some reported that schools had rejected them.

Almost all people in this category described instances of teasing, bullying or abuse, including sexual abuse. Often this is teasing by children, which is apparently deemed acceptable. Many people reported feeling fearful of drunk people who teased and abused them. Even family members tease and abuse their own family members with psychosocial disabilities. Such environments deter people from socialising, as one caregiver said, '(S)he cannot even socialise without being abused'. This results in people becoming withdrawn and anti-social and occasionally aggressive, which can actually increase the abuse. In such condition, people are unable to work, which reduces participation further. Some examples recorded were:

> A young man with severe psychosocial disabilities. He has experience abuse, stigma and discrimination that started at a young age for him and has continued ever since. He was expelled from primary school by a teacher who was not aware of his disability. The teacher slapped the boy and sent him home. He is totally reliant of others for his welfare and well-being, but apart from members of his household who love and understand him well, he is not getting any support from his community and the public at large. He is looked down upon and made fun of and disrespectful words and actions are directed at him.

> An older man who lives with relatives and has severe mental disabilities reported that small children often tease him and say mean things to make him angry. People discriminate against him because of his disability. A fieldworker reported that the place he is staying in is very dirty and that he was totally naked and he refuses to wear any clothes.

5.5 The situation in the outer islands: geography as a barrier

People living in the outer islands of Tuvalu feel particularly disadvantaged in regards to service provision for PWD and they expressed their views clearly. In particular they noted that outer island schools do not cater for children with disabilities; assistive devices are generally not available; there is a lack of accessibility for people with mobility impairments due to poor road conditions and no ramps in public buildings.

There were also reportedly high levels of teasing, bullying, abuse and discrimination of PWD in outer islands and a general feeling that there is a lack of awareness of the rights of PWD and how to care for them. As elsewhere, this was particularly the case for people with psychosocial disabilities. People in the outer islands repeatedly expressed the view that most services for PWD and for the elderly are in Funafuti.

Interviews with *kaupule* in the outer islands showed an awareness of PWD in their communities but they admitted that there are often negative attitudes in the community toward PWD which affects their participation, as well as a lack of facilities, with comments such as:

- PWD are not well respected. The main challenge is the behaviour of people towards them.
- They do not participate in community functions and activities.
- There is no access to the education system. There is discrimination and stigmatisation.
- Some PWD have been ignored by island people due to their bad behaviour and some really need special treatment.
- No ramps, roads are not good and they are inaccessible.
- No assistive devices, no special care; they are not respected by people; blind people cannot find their way around.

Kaupule members stated that they need public awareness on the rights of PWD to create an inclusive environment. One suggested enforcing customary laws on the care of PWD. They noted that mentally challenged people are often locked up in prison cells until they are considered not violent and no longer a threat to people in the community before being released to their families and that this process is carried out without any medical opinion or treatment. One *kaupule* commented that PWD with physical disabilities can be part of the community, but not those with mental / intellectual disabilities, reflecting the lack of understanding of people with psychosocial disabilities.

Fusi Alofa has assisted the establishment of committees in four islands: Nanumea, Nukulaelae, Nui and Nuitao. This study is required to assess the capacity of these committees in supporting the needs of PWD and their caregivers. Interviewees were asked whether they were members of FAA or an island disability committee. Very few respondents in the outer islands answered positively and when asked what assistance they got from the organisation, most said ‘none’. A few noted that they had received help in applying for the disability benefit and some found that socialising was positive. Fieldworkers reported that the outer island committees were not active, only getting together to celebrate World Disability Day in December. They apparently also have little contact with FAA in Funafuti. The assessment of the study therefore is that the capacity of the FAA affiliates in the outer islands is currently very limited.

5.6 Assistive devices: enabling or a barrier?

Assistive devices can make a huge difference to the lives of PWD, enabling them to function and participate in different aspects of life. The most commonly used assistive devices found in the study was glasses, with 23 per cent of those questioned using glasses. The second most used was walking sticks with 10 per cent followed by wheelchairs used by 8 per cent of participants, as shown in Table 10 below. Only one person reported using a hearing aid but said that it had been lost.

Table 10 Do you use any assistive devices?

Device	Men	Women	Total
Glasses	46	64	**110**
Hearing aid	1	0	**1**
Crutches	5	8	**13**
Walking stick	18	28	**46**
Walking frame	5	11	**16**
Wheelchair	16	21	**37**
Prosthetic limb	1	0	**1**
White cane (for visually impaired)	0	0	**0**
None	106	152	**258**
Others[33] – explain	5	2	**7**

Participants were then asked if they needed any assistive devices that they did not have and the results are in Table 11. This shows a great need for devices: only 13 per cent of participants said that they did not need any devices. The most commonly needed device was glasses, followed by wheelchairs, walking frames and hearing aids; with small numbers wanting other devices.

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[33] Others included commode, corner chair, broom stick as walking stick ,motorised wheelchair scooter, special shoes

Table 11 Do you need any assistive devices that you do not have?

	Men	Women	Total
Glasses	51	90	**141**
Hearing aid	15	26	**41**
Crutches	8	7	**15**
Walking stick	35	39	**74**
Walking frame	14	35	**49**
Wheelchair	26	65	**91**
Prosthetic limb	1	5	**6**
White cane (for visually impaired)	0	4	**4**
Commode	21	40	**61**
None	68	56	**124**
Others[34]	12	14	**26**

Fieldworkers were asked to find out whether the devices that PWD were using were in good condition. While 46 per cent of devices were in good condition, 39 per cent were not, and people needed new ones.

People with visual disabilities were asked if they knew Braille or used the Job Access With Speech (JAWS) screen reading software computer program. Only one responded positively to knowing Braille and no-one used JAWS. People with hearing disabilities were asked if they knew sign language and seven responded positively. A further 20 people with hearing disabilities said that they used or had developed a form of family sign language.

Assistive devices or mechanisms such as Braille, JAWS and sign language can be very empowering and can enable people with sight or hearing impairments to participate and lead fulfilling lives. There is a positive story of a deaf woman who knows sign language and who now has a full-time job at one of the hotels in Tuvalu. She is teaching another deaf women who works with her to use sign language. She also makes handicraft that she sells to supplement her income. Their employer is happy to have two deaf women work for her ‘as they are good workers and do not waste time gossiping among themselves like other workers’.

5.7 Hardship and disability: a barrier to a full life

Globally, persons with disabilities tend to have higher levels of hardship and poverty than those without. This is due to the higher costs incurred by the disabilities and to the fact that many PWD and their caregivers are unable to work, thus the households of PWD have lowered incomes.

The last question of the Tuvalu study asked the fieldworkers to make an assessment of whether or not the PWD was living in a situation of hardship and if they answered yes, to explain the reasons. During the fieldworker training, indicators of hardship were discussed and the fieldworkers showed a good understanding of the concept. The fieldworkers were looking for adequate living space; safety and cleanliness of living space; adequate care; indications of inadequate or insanitary toilet arrangements; evidence of poor water supply etc. The fieldworkers found 96 (20.6 per cent) cases of PWD living in situations of hardship. Some of the explanations they gave to justify their assessments included the following.

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[34] Others included: hospital bed, bedpan, club clutches, exercise bicycle, motorised wheelchair, physiotherapy belt, special shoes.

- Several cases were cited where PWD had difficulty with going to the toilet, due to severe disabilities, sometimes resulting in soiling themselves, resulting in an unhygienic environment. When PWD rely on others to take them to the toilet, their personal dignity is affected.
- Some PWD were found to be put in a small corner of the house with little social interaction of any kind and inadequate space to move around in. There were cases of unsafe environments: slippery floors; poor standard of housing; difficult access to outside toilets; or unsanitary surroundings.
- Other cases of hardship were due to the inability to work and support themselves and their families. This was a particular concern for those in the working age group.

5.8 Severe disabilities: a huge barrier to participation

This study demonstrates the range of degrees of disability. While some PWD are able to continue to live independent lives, those with very severe disabilities face barriers in almost every area of life, especially when the disabilities are multiple and life-long. Some examples that the study encountered include:

> PWD is a four year-old girl with cerebral palsy. She is unable to walk. She suffers from discrimination even within the family. A family member said, '(T)here are two infants in our family and I can see that members of our family prefer looking after the baby without disabilities'.

The family needs more financial support so that she can live a life with dignity.

> A man who became severely disabled after suffering a stroke recently, which was due to high blood pressure reported that everything in the community is now inaccessible for him – even his home. Has no devices and has had no physiotherapy for rehabilitation. He badly needs rehabilitation, a wheelchair, commode, diapers etc.

The care of PWD with severe disabilities poses a huge challenge for caregivers and many do not get respite from constant care. With assistance, both caregivers and PWD can live lives with more dignity.

5.9 Gender dimensions of the study

Women are affected by disability differently to men and, as pointed out above, there are more women PWD than men. This is in keeping with global trends and is attributed largely to the longer life expectancy of women compared to men. Gender and disability often combine to result in a double disadvantage for the women concerned.

Study participants were asked the question:

> Many people with disabilities face negative attitudes, bullying, harassment and even violence. Have you ever faced any kinds of negative attitudes, bullying, harassment or violence due to your disability? (study questionnaire question 63)

The responses show a clear gender bias: 72 women and 14 men responded that they had been subject to such negativity. This shows that women and girls with disabilities are in a particularly vulnerable position compared to men and were five times more likely to suffer from negative attitudes, bullying or harassment. Participants were given the option of enlarging on their answer and many did. The forms of abuse ranged from teasing, threats and verbal abuse from children and family members; sexual harassment and grooming; physical abuse including beatings and sexual violence including rape.

The study found that women with disabilities are more subject to sexual abuse than men, especially deaf women and women with psychosocial disabilities. Deaf women are generally unable to report abuse due to communication difficulties and women with psychosocial disabilities are unlikely to be believed. There is no indication that police are trained to deal with such situations.

The study confirmed that disabled women were twice as likely to face more hardship than disabled men. Fieldworkers assessed that 96 PWD were living in situations of hardship and of these 63 were women and 33 were men. The situations of these people vary, as explained in section 5.7, but the common factor is that they are not living lives of dignity, care or inclusion. These women face the triple burden of their gender, disability and poverty / hardship.

Participants were asked whether they had faced discrimination due to their disability. Of the 85 were replied positively, 41 were women and 44 were men. Implying that people were discriminated against on the grounds of their disability, not their gender.

A study into reproductive health and violence against women with disability in three Pacific Island countries found that there were high levels of violence against disabled women.[35] It is not possible to ascertain whether violence against women with disabilities is higher than the population at large in Tuvalu as there has not yet been a study into gender-based violence there. The same report found that women with disabilities generally had poor access to sexual and reproductive health as they were not seen as sexual beings. This did not emerge from the Tuvalu study where the overall usage of modern contraception usage is reported at 30.5 per cent.[36] Women who had their disability during their reproductive years were asked if they had had difficulty accessing family planning services and none reported that they had. The Tuvalu Family Health Association (TuFHA) told this study that disabled women can access its services if they are proactive but they do not make a concerted effort to reach such women.

One caregiver in the study reported that she took her relative who has severe psychosocial disabilities to TuFHA to get 'the family planning injection' every few months as she was often taken advantage of by men (sic).

Abortion is illegal and is socially condemned in Tuvalu. TuFHA and a prominent church person reported there is a cultural belief that disability is the result of a women attempting to procure an illegal abortion on her foetus. This reflects an attitude of shaming women and mothers who give birth to disabled children, which stigmatises not only the children concerned but also their mothers.

Education is free and compulsory in Tuvalu and there was no indication in this study that girls with disabilities are more disadvantaged than boys. Disability itself presents the main disadvantage in education. Participants were asked whether they had ever been refused access to school because of their disability. Of the 25 positive responses, 11 were women and 14 were men. When asked whether their disability was the reason for not going further in their education, of the 72 who answered yes, 31 were women and 41 were men.

The study showed some indication that women with disabilities participate less in family and community activities due to physical barriers compared to men with disabilities. When asked whether their disability was a reason for not participating, of the 135 positive responses, 99 were women and 36 were men. The reasons can only be speculated: it could be that there is no-one to assist them to surmount the physical barriers.

As discussed in section 6, the majority (78 per cent) of caregivers are women. This is an unpaid role which is an extension of women's traditional nurturing roles. The family is still seen as the main source of support and care for PWD as there are no alternative options such as residential care homes or institutions. Given traditional gendered roles, women tend to be the main carer even if other

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[35] United Nations Population Fund, *A Deeper Silence: The Unheard Experiences of Women with Disabilities – Sexual and Reproductive Health and Violence against Women in Kiribati, Solomon Islands and Tonga*, 2013,
[36] 2007, the latest data available.
http://www.wpro.who.int/countries/tuv/34_tuv_2012.pdf?subject=http://www.wpro.who.int/countries/tuv/34_tuv_2012.pdf

family members help out from time to time. Only seven PWD interviewed for the study were living alone, three women and four men. Caregiving is both physically and mentally demanding and it lacks recognition and caregivers receive very little support beyond basic benefits.

Overall, the study confirms that women carry the burden of disability disproportionately in Tuvalu, both in the numbers of women who have disabilities, in their roles as principal caregivers to disabled family members and that women are twice as likely to face hardship than disabled men.

5.10 What do PWD want to improve their Situation?

At the end of the questionnaire, PWD were asked an open-ended question: is there anything else you would like to add that could improve the lives of PWD in Tuvalu? Most participants (343 or 73.6 per cent) responded to this question and the responses are summarised in Table 12. (Note: some PWD mentioned more than one area of concern. Areas with less than 10 responses are noted in the footnote below[37]).

The clearest message from these responses is that the role of providing for PWD is seen to be the Government's role, whereas traditionally it has been the role of families. The study shows that while families still take care of PWD on a daily basis, people are increasingly looking for Government support. While a large number of people called for unspecified Government support, there were also strong calls for meeting financial needs, health-care and education.

Table 12 Improving the lives of PWD

Item	No.
Need unspecified GOT support	63
Financial help	36
Increase benefits	26
Lower benefit age / criteria	21
Build a centre for PWD	41
Improve awareness of rights of PWD	36
Protect, care, love, respect PWD	31
Improve education for PWD	27
Improve assistive devices	12
Help for outer islands	21
Better health care	14
Facility for people with psychosocial disabilities	11
Freedom from harassment & discrimination	10

What is largely missing from much of this discourse is a focus on empowerment of PWD such as enhancing their opportunities in life, although the strong calls for improvement of education and for improving the awareness of rights of PWD are encouraging signs.

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[37] Small numbers of people called for improvement in laws and policies; improve accessibility; support FAA; specialist medical services; help with housing; need for more trained caregivers.

6 What are the current support mechanisms for PWD and how successful are they are at providing support to PWD?

The GOT provides services but many are not specifically targeted towards PWD. With some adaptations, they could be improved to progress the lives of PWD in Tuvalu, thus eliminating barriers and promoting a more inclusive society.

6.1 Education

Education can be an enabling factor to enhancing life chances or a barrier to success if educational experiences are negative. The majority of PWD in the study had been to primary school at some stage as shown in Table 13. However, the study was not able to ascertain whether PWD had completed primary school or not. Anecdotal comments from parents and caregivers indicated that many children had not completed the primary school cycle.

Table 13 School level

	Men	Women	Total
None	20	22	42
Pre-school	6	3	9
Fusi Alofa	7	5	12
Primary	105	178	283
Secondary	42	43	85
Tertiary	15	20	35
Total	**195**	**271**	**466**

PWD were asked whether their disability was a reason for not continuing their education. This was not applicable in the cases on adult onset of disability, accounting for 329 or 70 per cent of all cases. However 72 (15 per cent) of all PWD stated that they did not continue their education due to their disability. When asked if they had been refused access to school due to disability, 25 people responded positively. In most cases where a PWD had never been to school, parents stated that they chose for their child not to attend school. A small number of children attend the FAA school. There was no significant gender differences, although more men replied that they did not continue school due to their disability (31 women compared to 41 men). The situations of the participants noted below illustrate some of the challenges they face in attending school:

- Child less than ten years' old who was born with psychosocial disabilities attends FAA. His mother wants him to get the proper education he is entitled to in order for him to live his life with independence and dignity. She wants him to enjoy his right to education. He suffers from being teased by other children due to his mental disability.
- Another child around eight years old, with severe visual disabilities and communication difficulties from birth, attends FAA. Has been refused entry to mainstream school as teachers are not able to teach her.

Despite the fact that many children with disabilities attend primary school, they are poorly served on the whole by the education sector and many children with disabilities are not fully enjoying their right to education. Despite its intentions at the policy level, the Department of Education does not keep data on children with disabilities or learning difficulties and has no specific policy or strategies for their education. This is partly because there is no systematic process for assessing children who may have disabilities or learning difficulties and it is largely an unknown terrain. The absence of knowledge or data means that there is no evidence to base policies upon. Even the few teachers who are trained in special or inclusive education are not engaged for that purpose in a sustained manner. Teachers who were interviewed for the study said that they do not have individual learning programs for children with disabilities but that they try to include them the best they can.

People recounted to the study how teachers threaten children that ‘they will have to go to Fusi Alofa’ if they do not achieve well, which is extremely demeaning. In fact the term ‘Fusi Alofa’ has come to be synonymous with disability in Tuvalu and is sometimes used as a term of abuse.

There were numerous comments made to the study that there should be more special schools and centres for children and youth with disabilities. However, this is contrary to contemporary thinking, that PWD should have the right to fully participate in mainstream education: inclusive rather than segregated ‘special education’. In a small country, inclusive education is realistically the only option. This thinking of wanting to separate children with disabilities into separate schools demonstrates a pervasive lack of understanding of the rights of PWD. It could be argued that the current system is inclusive, as children with disabilities often attend mainstream schools. However, without any individual educational programs or support services, the system fails such children as the testimonies in this study bear witness to.

6.2 Health care

While people were not specifically asked questions on their experiences in the health system, numerous PWD and their carers cited the need for specialist attention especially psychiatric care which is almost completely lacking. Other needs for medical care included physiotherapy in particular rehabilitation, eye care and hearing tests.

In terms of accessibility, almost half of the participants said that the hospital or health centre was inaccessible to them (see Table 9).

Outer island nurses who were interviewed for the study said that in all islands except one (Nanumea), there was no specific help for PWD. In most islands they have occasional access to assistive devices but not enough to meet the need.

A third of all PWD reported taking medication on a regular basis. Of the 40 people with epilepsy, only 14 took daily medication.

Women who were in the reproductive age group were asked whether they had had any difficulty accessing family planning / birth control services. A very small number of women responded positively but in fact they did not have their disabilities at the time of the incidents and it was not difficulty accessing services as such, rather side-effects of birth control that were reported.

6.3 Beneficiaries

The study identified 73 recipients of the GOT’s disability benefit and 113 recipients of the age benefit described at the start of this report. The main comment on the benefit was that it was insufficient to meet the costs of living and should be increased. Several people also commented that the age should be reduced for the age benefit.

One issue that arose was that in some cases, relatives collect the benefit and allegedly use it for purposes other than caring for the PWD or elderly person.

Participants were asked whether they received any assistance from other sources and 52 per cent acknowledged that they did. In most cases, this was from churches, followed by the Red Cross, youth groups, women’s groups and community groups. The main forms of assistance were visits and gifts especially of toiletries. The 48 per cent who did not receive other forms of support tended to be those with minor disabilities and people with psychosocial disabilities.

6.4 Caregivers

Many PWD do not need a caregiver as those with mild disabilities are able to live fairly independent lives. When questioned on caregivers, 319 PWD participants in the study stated that a family member was their caregiver, 3 a non-family member, while 142 said that they did not have or did not need a caregiver. Seven PWD reported living alone while the rest lived with various family members. There were very few cases where fieldworkers reported that PWD were not well cared for by caregivers or family members.

Table 14 Caregivers

	Men	Women	Total
Family member	133	186	319
Not family		3	3
Don't have or don't need a caregiver	61	81	142
Not stated	1	1	2
Total	**195**	**271**	**466**

Note: the gender refers to the PWD not the caregiver

Of those who had caregivers, the relationships varied, as Table 14 shows. The study interviewed 97 caregivers of PWD, all of whom were family members of the PWD. Seventy (78 per cent) were women and 23 (22 per cent) were men. Three women were the caregivers of two PWD, thus were counted twice in the study. Fieldworkers reported that several caregivers declined to be interviewed.

The purpose of the interviews with caregivers was to find out how long they had looked after the PWD in their care; what challenges they faced; what support was needed to make their life easier; and whether they or the PWD in their care had faced any teasing, harassment or bullying due to disability.

Table 15 Relationship of caregiver to PWD

Relationship	Men	Women	Total
Spouse	41	24	65
Parent	35	23	58
Child	28	88	116
Grandchild	3	10	13
Niece / nephew	6	7	13
All members of the household look after the PWD	19	30	49
Other	1	5	6
Not stated	1	3	4
Total	**134**	**190**	**324**

Note: gender refers to PWD, not caregiver;others were most frequently siblings

The length of time of caregiving varied from one year to 48 years. In many cases, it was for the entire lifetime of people, especially those born with severe or psychosocial disabilities.

The challenges faced by caregivers varied but can be grouped into broad categories as follows:

- Physical difficulties linked to personal hygiene and toileting including lifting and carrying PWD.

- Difficulties dealing with mentally ill or senile persons including coping with their (occasional) violence; constant need for supervision; communication difficulties. Difficulties are increased for those caring for people with epilepsy who have frequent seizures. A small number of caregivers face physical threats and abuse from the people they care for.
- Lack of assistive devices to help, in particular wheelchairs and commodes.[38]
- Stress and tiredness from constant demands.
- Financial difficulties coping with extra needs of PWD such as diapers.

Caregivers were asked what they needed to make their lives easier. Their needs are grouped broadly as:

- financial help;
- psychiatric or other medical assistance;
- education, training including vocational training and training for independent living and sign language;
- assistive devices including wheelchairs, walking frames, commodes, hearing aids and glasses; and
- rehabilitation.

Some caregivers of children and youth with disabilities worried about their future once they are no longer able to take care of them and they hoped for education and training in independent living for their children.

The widespread abuse, stigma and bullying towards PWD is discussed in section 5.3. Caregivers also cited several examples of bullying, teasing and harassment of the PWD they cared for. Sometimes the caregivers find it difficult to report cases of abuse because it's within families or the perpetrators are family. These were notably for people with psychosocial disabilities, deaf people and those with visible disabilities. Older people with disabilities generally, but not always, faced less abuse. There is clearly an emotional impact on caregivers when PWD are bullied and abused. They reported feeling angry and upset when their family members suffered from abuse and discrimination. The following quotes provide some examples, as the study participants noted:

> 'Many times I experience anger because of the discriminatory attitude of people towards my child.'
>
> 'Yes, I am greatly affected by these negative behaviours and actions as I often see children and even adults ill-treat him with verbal abuse and poking fun at him.'
>
> '(My child) has been beaten up by people many times and it breaks my heart to see him like that.'
>
> 'Some people tease me about my brother that he is mental and needs to go to Fusi Alofa.'
>
> 'He was sexually abused by a man.'
>
> 'My brother is always discriminated against by people so many times. That is why I do not want to take him anywhere.'
>
> None of the caregivers interviewed talked directly about what they might be doing if they were not looking after their disabled relatives, but many commented on their financial difficulties especially when no-one in the household was working, they said:

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[38] A commode is a chair with a portable toilet that can be placed at the bedside of a person whose activity is limited.

> ‘Overall it is good but since I’m not employed I really do need financial support to take care of my son.’
>
> ‘We need financial help for our child’s needs and well-being seeing that both of us parents are no longer employed or earning money.’

There is no formal system of support for caregivers in Tuvalu as the responsibility for care is left to families. There is a widespread assumption that families take on this role unquestioningly. While family support generally works, it may be only a matter of time before there is a shortage of caregivers especially for older persons and especially for older women, due to the relatively high rates of outward migration from Tuvalu and from outer islands to Funafuti. There is little knowledge or understanding of issues of old age such as senility and dementia, which are growing in frequency as people live to older ages. There is no system of support for making homes accessible when a family member has mobility difficulties.

There were cases of hardship, cited elsewhere in this report, that show that some PWD do not have adequate care but it was not possible to quantify the extent of this. Comments from this study show that some caregivers have a desperate need for medical care and for assistive devices and there is no service provider who easily can fill the need especially for home-based care.[39]

7 What are appropriate actions or interventions that can be put in place to improve the support for PWD in Tuvalu?

Despite the strong calls for increases in benefits, this study is not recommending increases as a long-term strategy for improving the lives of PWD in Tuvalu as it recognises the many competing demands on the GOT’s treasury and the increasing number of beneficiaries. The recommendations are for strategic, sustainable and achievable interventions, to support and strengthen existing processes, all of which are aligned to CRPD Articles. It should be noted however that many recommendations overlap different Articles of the CRPD. All of the recommendations are based on the CRPD fundamental concepts of respect for the inherent dignity and autonomy of persons with disabilities, non-discrimination, participation, inclusion, equality, and accessibility (Article 3). The recommendations are directed primarily towards stakeholders in Tuvalu. Key implementing agencies and potential partners have been suggested. Based on the findings of this study, the following recommendations are made:

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.

CRPD Article 33: National implementation and monitoring.

Implementing agencies / partners: Ministry of Home Affairs as lead, all parts of the GOT, Fusi Alofa.

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

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[39] The FAA teacher visits some older PWD and some children with disabilities on a weekly basis. Churches provide gifts on an ad hoc basis, especially at Christmas time.

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.

CRPD Article 6: Women with disabilities

CRPD Article 28: Adequate standard of living and social protection

Implementing agencies / possible partners: Ministry of Home Affairs, FAA, churches, civil society, Pacific Women Shaping Pacific Development.

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

CRPD Article 4: General obligations

CRPD Article 5: Equality and non-discrimination

CRPD Article 12: Equal recognition before the law

CRPD Article 13: Access to justice

Implementing agencies / partners: Attorney General's Office, DFAT.

Recommendation 4. Laws: the laws of Tuvalu need to be reviewed and aligned to the CRPD, as per the GOT's obligations under the CRPD.

CRPD Article 4: General obligations

CRPD Article 5: Equality and non-discrimination

CRPD Article 12: Equal recognition before the law

CRPD Article 13: Access to justice

Implementing agencies / potential partners: Attorney General's Office partners; UNESCAP and Pacific Islands Forum Secretariat.

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:

- 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.

CRPD Article 8: Awareness-raising

CRPD Article 10: Right to enjoyment of life

CRPD Article 33: National implementation and monitoring

CRPD Article 20: Personal mobility

Implementing agencies / potential partners: Fusi Alofa, Ministry of Home Affairs, DOE, MOH, Pacific Disability Forum, Disability Rights Fund, Motivation Australia, SPC/RRRT, Radio Tuvalu.

Recommendation 6. Education: the Department of Education can improve educational opportunities for children with disabilities to build an inclusive society for all, including:

- Fully implement TESPIII; finalise Inclusive Education (IE) 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 IE 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.

CRPD Article 5: Equality and non-discrimination.

CRPD Article 7: Children with disabilities.

CRPD Article 10: Right to enjoyment of life.

CRPD Article 24: Education

Implementing agencies / potential partners: DOE, FAA, Fiji Volunteer Teachers Scheme, University of the South Pacific, DFAT.

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.

CRPD Article 25: Health

CRPD Article 26: Habilitation and rehabilitation

CRPD Article 20: Personal mobility

Implementing agencies / potential partners: MOH, bilateral partners, WHO.

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;
- provide a link between health providers and caregivers.

CRPD Article 6: Women with disabilities

CRPD Article 23: Respect for the home and the family

Implementing agencies / potential partners: potentially the Red Cross and / or TuFHA, faith-based organisations, FAA. (Note: FAA is doing this to some extent but there needs to be a more coordinated approach).

8 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.

Annex 1 Terms of Reference People With Disability Study, Tuvalu

Program background

Pacific Women Shaping Pacific Development (*Pacific Women*) was announced by the Australian Government at the Pacific Island Leaders' Forum meeting in August 2012. It commits up to $320 million over 10 years in the 14 Pacific Islands Forum members. The program aims to improve opportunities for the political, economic and social advancement of Pacific Women. It does this through a focus on four distinct but interconnected objectives:

- increase women's leadership and influence in decision-making, including at local government level;
- increase economic opportunities for women;
- strengthen national responses to violence against women and provide expanded support services; and,
- enhance knowledge and evidence to inform policy and practice.

Pacific Women is implemented by Australia's Department of Foreign Affairs and Trade (DFAT) and works with a wide range of implementing partners, including the 14 partner governments, multilateral organisations, international and national NGOs, civil society organisations, and DFAT country posts.

The *Pacific Women* Support Unit provides the program with logistical, technical and administrative support and is located in Suva, Fiji, with a sub-office in Port Moresby, Papua New Guinea (PNG).

Pacific Women in Tuvalu

In 2013, DFAT – in consultation with the Government of Tuvalu, nongovernmental organisations and communities – formulated the Tuvalu *Pacific Women* country plan (2015–2018). The country plan was endorsed by the Tuvalu Government on 15 October 2015. The country plan outlined the Australian Government's commitment to spend up to $1.8 million over three years (2015–2018) on initiatives that support women's empowerment in Tuvalu.

The Tuvalu country plan is aligned with the Government of Tuvalu's gender and development policy and reflects the concerns, needs and priorities of women, girls and persons with disabilities (PWD) in Tuvalu. The Tuvalu country plan identifies six primary objectives:

- reducing violence against women and expanding support services;
- enhancing the evidence base to inform policy and practice;
- strengthening women's organisations, groups and coalitions for change;
- improving women's leadership and decision-making opportunities;
- increasing economic opportunities for women; and
- improving gender outcomes in health and education.

Disability in Tuvalu

Global and regional studies suggest that PWD are the most disadvantaged groups in society. Women and girls with disabilities are particularly vulnerable to sexual and physical violence and abuse. Some people with disabilities are neglected and/or emotionally, physically or sexually abused, while others are overprotected by their families and denied the opportunity to meaningfully participate in their communities. They also lack access to quality sexual and reproductive health services. Sometimes, they are unfairly labelled and stereotyped, which leads to loss of self-esteem and depression. There also often is insufficient protection from discrimination and ongoing stigmatisation.

The Tuvalu 2012 Census reported that there are about 200 PWD in Tuvalu or 2 per cent of the population under the age of 60. This figure is low in relation to other Pacific countries and the global average. Often low prevalence rates are reported when the survey carried out does not ask the right questions around functioning and abilities.

PWD in Tuvalu live with their immediate family members and are looked after by women relatives. Little is known about their life circumstances. In 2012, disability data in Tuvalu were collected by the New Zealand-funded project, *Supporting Local Governance for Outer Islands Development Phase II* (SLG II), which was administered by UNDP. The disability statistics in the SLG II project findings are much higher and showed the common forms of disability per island in Tuvalu. According to the SLG project, the most common forms of disabilities in Tuvalu are physical disability, hearing impaired and mobility-disability related. The total number of PWD is not clear from the findings but it is estimated to be at around 430. The data also showed that there are more women with disabilities than men with disabilities in Tuvalu.

The lack of information on PWD has hindered relevant stakeholder efforts to promote and support interventions for PWD in Tuvalu. In 2013, Tuvalu ratified the Convention on the Rights of People with Disabilities (CRPD). It is expected that reporting obligations under the Convention are due soon and the findings from this study will provide useful information for reporting under this Convention.

One of the key priority activities identified in the *Pacific Women* Tuvalu country plan (2015–2018) is to provide short-term technical assistance to the Tuvalu Disability Persons Organisation, Fusi Alofa Association of Tuvalu, and to the Ministry of Home Affairs to conduct a disability study. The study will collect information about the experiences of PWD and their carers. It will include an examination of the barriers they face – including physical, communication, attitudinal and institutional – to create a holistic picture of the challenges experienced in their everyday life.

Purpose of study

The purpose of the *Pacific Women* People with Disability (PWD) study is to carry out research that focuses on PWD in Tuvalu. This study will inform policy and program development that addresses the needs of PWD and their caregivers in Tuvalu.

The study will aim to:

- provide detailed qualitative and quantitative information to service providers and key stakeholders on the situation of PWD in Tuvalu;
- contribute information to Tuvalu’s first reporting under the CRPD; and
- inform future policy and programming on gender equality and social inclusion in Tuvalu.

Objectives

The objectives of the study are to:

- collect data and information on PWD in Tuvalu to assist key stakeholders in developing the baseline information for their reporting under the CRPD;
- identify the barriers that are faced by PWD and their caregivers in accessing services in Tuvalu as well as the social and attitudinal barriers they face;
- assess the capacity of existing outer island disability committees and/or organisations in supporting the needs of PWD and their caregivers; and
- identify relevant strategies to improve support for PWD in Tuvalu.

The study is to take an empowering approach and actively engage with PWD in the design, implementation and analysis processes.

The study will be led by a consultant, who will work in consultation with key stakeholders in Tuvalu and the Pacific region, including agencies specialising in issues of gender and disability.

The consultant is expected to work in partnership with the key partners in Tuvalu, including:

- Gender Equality and Social Inclusion Adviser and the Gender Affairs Department;
- Fusi Alofa Association Tuvalu;
- Community Affairs Department; and
- Statistics Department.

Specific questions to be answered by the study

The study must be able to answer the following key questions:

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

List of intended users of the work

- The Government of Tuvalu, service providers responsible for disability and gender equality services and support.
- Australian Government, including the Department of Foreign Affairs and Trade and *Pacific Women* program staff.
- Stakeholders and partners implementing disability-focused programs in Tuvalu.
- Other development partners interested in working on disability issues in Tuvalu.
- Pacific governments implementing PWD initiatives will use the report to inform policies and programs and human rights reporting on inclusion of PWD.
- Civil society organisations.

Selection criteria

The consultant should have the following skills and experience:

- Relevant post-graduate tertiary qualifications (particularly in women- and gender-related fields, social inclusion or disability-related mixed methods research).
- At least 10 years' experience in the design and conduct of mixed methods research.
- A strong background and understanding of disability issues in the Pacific, including evidence of working with PWD for a period of 10 years or more.
- Strong written and analytical skills.
- Excellent interpersonal skills and ability to adapt communication to different audiences.
- Track record of successful consultancies.

Key references

- A Deeper Silence (UNFPA)
- Development for All 2015–2020: Strategy for strengthening disability-inclusive development in Australia's aid program
- Government of Tuvalu CEDAW, UPR State and NGO reports
- Government of Tuvalu 2015 National Budget
- Government of Tuvalu 2016 National Budget
- Government of Tuvalu Poverty Lines, the Incidences and Characteristics of Poverty in Tuvalu
- Government of Tuvalu Demographic and Health Survey
- Government of Tuvalu Family Protection and Domestic Violence Act

- Government of Tuvalu, UNDP and New Zealand Ministry of Foreign Affairs & Trade Aid Programme, 2012 Island Profiles (for Nanumea, Nanumaga, Niutao & Niulakita, Nui, Vaitupu, Funafuti, and Nukulaelae)
- DFAT's Disability Inclusive Development: http://dfat.gov.au/aid/topics/development-issues/disability-inclusive-development/Pages/disability-inclusive-development.aspx
- Making Women with Disabilities Visible
- Mapping of the disability policy and program frameworks in the Pacific
- Pacific Children with Disabilities
- Pacific Sisters with Disabilities at the Intersection of Discrimination
- Pacific Women Delivery Strategy
- Pacific Women Tuvalu Country Plan
- Pacific Women Monitoring and Evaluation Framework

Annex 2 Additional Tables

Table 1: Disabilities by island, based on Washington Group of questions

	Difficulty seeing[40]				Difficulty hearing			
	2	3	4	Total	2	3	4	Total
Nanumea	12	5		17	4	4		8
Nanumaga	8	5	1	14	4	3		7
Niutao	11	3	1	15	3	4	1	8
Nui	18	12		30	8	5	1	14
Vaitupu	28	11	2	41	14	7	3	24
Nukufetau	14	4		18	4	4		8
Funafuti	109	34	4	147	39	25	9	73
Nukulaelae	3	1		4			2	2
Niulakita						1		1
Total	**203**	**75**	**8**	**286**	**76**	**53**	**16**	**145**

	Difficulty walking				Difficulty remembering			
	2	3	4	Total	2	3	4	Total
Nanumea	11	7	4	22	5	11	1	17
Nanumaga	4	7	8	19	6	2	1	9
Niutao	9	4	5	18	7	2	1	10
Nui	12	6	11	29	11	1	4	16
Vaitupu	17	15	9	41	21	9		30
Nukufetau	10	2	4	16	8	3		11
Funafuti	80	50	43	173	86	37	11	137
Nukulaelae		2	4	6	5	1		6
Niulakita						1		6
Total	**143**	**93**	**88**	**324**	**149**	**67**	**18**	**237**

	Difficulty self-care				Difficulty communicating			
	2	3	4	Total	2	3	4	Total
Nanumea	8	2	1	11	6	4	2	12
Nanumaga	4	3	7	14	4	4	1	9
Niutao	6	2	3	11	1	4	1	6
Nui	2	2	8	12	5	3	1	9
Vaitupu	10	3	5	18	10	3	3	16
Nukufetau	4		2	6	3	1		4
Funafuti	56	30	22	108	64	41	11	116
Nukulaelae	1	3		4	3	1		4
Niulakita			1	1		1		1
Total	**91**	**45**	**49**	**185**	**96**	**62**	**19**	**177**

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[40] 2 refers to some difficulty; 3 to a lot of difficulty; 4 to unable to do that ability

Table 2 Summary of prevalence of disabilities by island

Island	Seeing	Hearing	Walking	Remembering	Self-care	Communicating
Nanumea	17	8	22	17	11	12
Nanumaga	14	7	19	9	14	9
Niutao	15	8	18	10	11	6
Nui	30	14	29	16	12	9
Vaitupu	41	24	41	30	18	16
Nukufetau	18	8	16	11	6	4
Funafuti	147	73	173	134	108	116
Nukulaelae	4	2	6	6	4	4
Niulakita	0	1	0	1	1	1
Total	**286**	**145**	**324**	**234**	**185**	**177**

Island	Seeing	Hearing	Walking	Remembering	Self-care	Communicating
Nanumea	57%	27%	73%	57%	37%	40%
Nanumaga	70%	35%	95%	45%	70%	45%
Niutao	60%	32%	72%	40%	44%	24%
Nui	81%	38%	78%	43%	32%	24%
Vaitupu	67%	39%	67%	49%	30%	26%
Nukufetau	67%	30%	59%	41%	22%	15%
Funafuti	58%	29%	68%	53%	42%	45%
Nukulaelae	40%	20%	60%	60%	40%	40%
Niulakita	0%	100%	0%	100%	100%	100%
Total	**61%**	**31%**	**70%**	**50%**	**40%**	**38%**

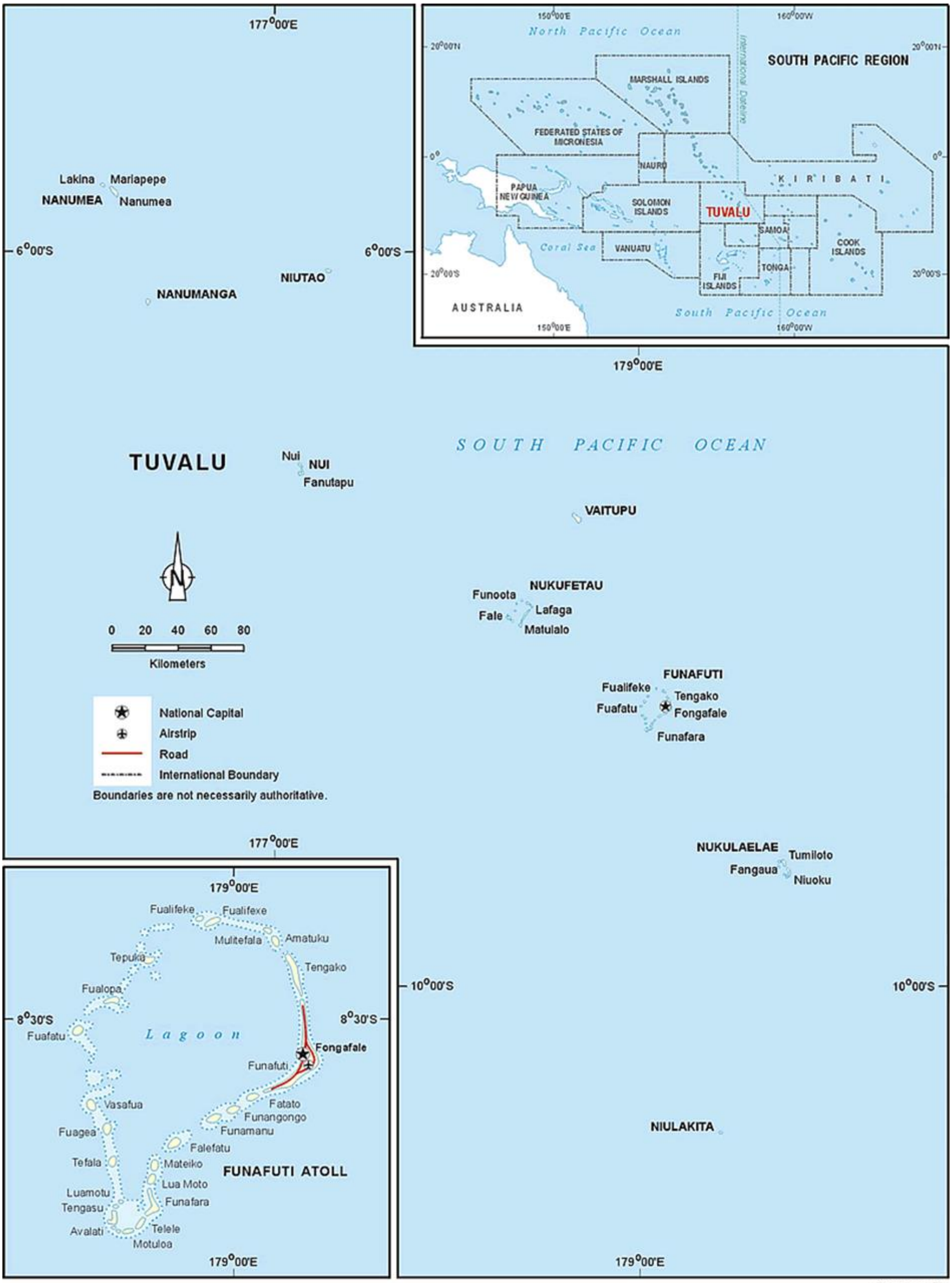
Table 3 Age of onset of disability by island

Island	Age of onset of disability					
	From birth	0–20	21-60	61+	Don’t know	Total
Nanumea	5	4	13	7	1	30
Nanumaga	1	2	10	4	3	20
Niutao	6	3	5	9	2	25
Nui	5	1	15	12	4	37
Vaitupu	7	2	21	28	3	61
Nukufetau	2	4	9	12		27
Funafuti	49	27	89	82	8	255
Nukulaelae	2	2	1	4	1	10
Niulakita		1				1
Total	**77**	**46**	**163**	**158**	**22**	**466**

Table 4 Age of onset of disability by age groups

	Men	Women	Grand Total
0-5	55	49	104
6-10	5	2	7
11-15	6	2	8
16–20	2	2	4
21–25	4	2	6
26-30	6	2	8
31-35	5	2	7
35-40	4	3	7
41-45	7	9	16
46-50	7	14	21
51-55	11	25	36
56-60	21	41	62
61-65	24	37	61
66-70	15	28	43
71-75	8	14	22
76-80	5	12	17
80+	3	12	15
Don't know	7	14	21
Not stated		1	1
Total	**195**	**271**	**466**

Annex 3 Map of Tuvalu



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Annex 4 People Consulted

Name	Organisation	Position
Eseta Lauti	RRRT/ SPC	Country focal officer
Nese Ituaso-Conway	Princess Margaret Hospital	Director of Health
Efron Jogia	Office of the Attorney General	Senior Crown Counsel
Alice Are	Fusi Alofa Association	Special Needs Teacher
Matakina Simii	Fusi Alofa Association	Office Manager (outgoing)
Ioane Hawaii	Fusi Alofa Association	Youth member
Esekia Vaiga	Fusi Alofa Association	Board member
Lanieta Faleasiu	Ministry of Home Affairs	Community Affairs Officer
Maho Homasi	Ministry of Home Affairs	Social Analyst
Sopoaga Saufatu	Tuvalu Red Cross	General Secretary
Neaki Letia	Ministry of Education, Youth & Sports	Acting Director of Education
Pamela Lysaght	Ministry of Education, Youth & Sports	Education Planning Adviser, Technical Adviser
Grace Alapati	National Statistics Office	Acting Government Statistician
Rev Tafue Lusama	EKT	General Secretary
Lono Leneuoti	Tuvalu Family Health Association	Executive Director
Teimama Avantele,	Ministry of Education, Youth & Sports, (MEYS)	ECCE officer
Betty Vave	Ministry of Education, Youth & Sports, (MEYS)	School Supervisor
Alapati Rick Taupo	Ministry of Education, Youth & Sports, (MEYS)	School Supervisor, ICT