

# Understanding disability support systems in the Pacific

## Stories of people with disability and support persons

Version: Final 19<sup>th</sup> December 2025



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## Acknowledgements

The team at the Nossal Institute and CBM Australia are grateful to our OPD partners - Pacific Disability Forum, Fusi Alofa Association Tuvalu, and Fiji Disabled Persons Federation - for their guidance, expertise and support throughout the development of these stories.

We thank all participants for generously sharing their experiences and perspectives as part of the qualitative study that contributed to these stories. We also remember and pay tribute to Molomolo Touaisi and Taupaka Uatea, office managers of Fusi Alofa Association Tuvalu, who sadly passed away during the course of this project.

## Disclaimer

*This publication was prepared under the DFAT – CBM Inclusion Advisory Group Disability Inclusion Technical Partnership, an Australian aid initiative implemented by CBM Inclusion Advisory Group and the Nossal Institute for Global Health at the University of Melbourne.*

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

*Please respect the integrity of this content and refrain from editing or altering the stories in any way.*

## Introduction

Disability support services are essential for promoting the independence, dignity, wellbeing, and equal participation of people with disability. Recognised as a key precondition to inclusion under the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the Pacific Disability Forum's Preconditions for Inclusion Framework, disability support services are a priority to ensure equity for people with disability, and crucial for achieving the Sustainable Development Goals (SDGs).<sup>1,2,3</sup>

In the Pacific, understanding the context, current landscape and needs around disability support services is essential to developing appropriate, locally relevant responses that strengthen supports for people with disability and their support persons. The Pacific Disability Forum called for a shared understanding of what disability support services mean in the Pacific context. In response, a study was conducted with collaboration between the Nossal Institute, CBM Australia, the Pacific Disability Forum, Fiji Disabled Persons Federation, and Fusi Alofa Association Tuvalu, funded by the Australian Department of Foreign Affairs and Trade (DFAT).

The study explored existing supports and gaps for people with disability and their families in Fiji and Tuvalu, and proposed a framework to guide advocacy, policy and action on disability supports tailored to Pacific Island countries—documents containing the Framework and the Methods and Findings of the study can be found separately.

This document presents six stories designed to illustrate and communicate insights from key experiences and issues identified in the study. Each story draws on experiences from several participants and are not necessarily reflective of one individual's real-life experience. The stories can be used for training, advocacy, workshops and presentations.

### How were the stories developed?

The study included in-depth interviews with people with disability (n = 6), support persons (n = 8) and select stakeholders (n = 7) in Fiji and Tuvalu. Interviews explored disability support needs, how supports are currently provided, the impact of supports and support gaps, as well as challenges and enablers in accessing supports in Fiji and Tuvalu contexts. A full description of the methods, analysis and results from the study can be found in the separate Methods and Findings document.

Findings from the interviews were analysed and synthesised to form the basis of the stories. An initial storyboarding process involved the identification of main themes and subthemes for each story. Themes and subthemes were chosen to illustrate a diversity of support needs, impairment types, genders, living circumstances, as well as environmental and contextual factors relating to family and household arrangements, income status, and differences in urban, rural and remote living.

While the stories are based on the accounts of research participants, identifiable information and narrative elements were altered by the researchers to protect participants' identities and represent multiple issues. Due to study limitations, the stories do not represent the full diversity of experiences and issues reported by participants.

### What do the stories include?

Each story presents a fictional persona and narrative illustrating the support needs, provision of supports, unmet support needs, and barriers and enablers to improving access to supports from the perspective of a

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

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

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

person with disability or a support person. An analysis box at the end of each story uses the ‘continuum of needs’ (outlined in section 4 of the accompanying framework document – ‘A framework for understanding disability support systems in the Pacific’). The analysis box highlights support needs of the personas in the stories, across the 3 layers: 1) Support Services, 2) Empowerment and Capacity Building Programs, and 3) Accessible and Enabling Environments.

Table 1 below provides an overview of the stories and personas, including personal attributes (genders, ages, impairment types, support needs) and key themes included in each story.

**Table 1:** Summary of personas and story contents

Story	Persona	Impairment type	Main supports required	Setting, Country	Key themes
1	Tiko, male with disability (42 years)	Physical	Mobility, AT, self-care, home modifications, income	Urban Fiji	Physically inaccessible environment, low-income household, sudden loss of independence
2	Hina, female support person (39 years)	None	Respite	Rural Fiji	Livelihoods skills training, social isolation, attitudinal barriers and stigma, gender-based violence
	Afiya, female with disability (20 years)	Hearing	Communication, learning		
3	Mareoni, female support person (38 years)	None	Respite, income	Island, informal settlement Fiji	Physically inaccessible environment, kinship dynamics, flood emergency, disaster preparedness and response
	Alisi, female with disability (16 years)	Physical and intellectual	Communication, mobility, AT, rehabilitation, income, home modifications		
4	Filo, male with disability (35 years)	Vision	Mobility, transportation, rehabilitation	Remote Tuvalu	Inaccessible public infrastructure and transportation, income generation and livelihoods, circles of support
5	Lagi, female support person (46 years)	None	Respite, skills training, crisis supports	Remote Tuvalu	Mental health crisis supports, trauma-informed care, gender- and family-based violence
	Fiafia, female with disability (24 years)	Psychosocial and cognitive	Emotional, cognitive, behavioural, safety		
6	Sila, female support person with disability (34 years)	Physical	Transportation, AT, transport modifications	Island Tuvalu	Inter-island mobility, inaccessible maritime

Story	Persona	Impairment type	Main supports required	Setting, Country	Key themes
	Tupulaga, male with disability (7 years)	Autism spectrum	Learning, task modifications		transportation, inclusive education, emigration

### How can the stories be used?

The stories and accompanying Framework may be used by any person or organisation with an interest in understanding or progressing disability support systems for people in Pacific Island countries. The stories can be used as part of presentations, workshops, and media communications to illustrate, draw attention to, and generate discussion about the experiences of people with disability and support persons and key issues and challenges with improving access to disability support systems in the Pacific. It is anticipated that OPDs, governments, donors, implementing agencies, and others will use the stories and Framework to support advocacy, planning and implementation of disability support services and systems.

#### **Example: group exercise (30 to 45 minutes)**

Step 1: Break the room into small groups and assign a different story to each group.

Step 2: Allow each group 5 minutes to read the story in full.

Step 3: Each group takes 10 minutes to analyse and discuss the story, using the Disability Support Systems Ecosystem Template (in Appendix A of the Framework) to identify factors at each layer impacting on the need and access to disability supports.

Step 4: Each group takes 2 to 3 minutes to briefly present their story and ecosystem analysis.

Step 5: To finish, hold an open discussion about the differences and similarities between each groups' ecosystem analysis, then consider strategic actions for improving access to supports.

Optional: Use Appendix B: Action Plan Template to facilitate group discussion on identifying strategic actions for strengthening access to supports in a country context.

## Story 1 – Tiko, Fiji

Tiko is a 42-year-old iTaukei man. He lives with his wife, two young children and elderly mother in Suva. Two years ago, Tiko broke his legs in a car accident. One leg had to be amputated. Now he uses crutches and a wheelchair to move around and requires support with many of his daily activities.

“After the accident, everything changed. At first, I couldn’t stand or walk at all. The hospital staff at the rehabilitation ward taught me how to use crutches. The OPD gave me a wheelchair, which I use to go outdoors. I lost my job at the construction company because I can’t do physical labour anymore. My wife reduced her hours as a cleaner so she could support me at home.”

Because Tiko is still regaining strength in his leg, he requires support to stand up and sit down. Usually, his wife assists him to get out of bed, to stand up from a chair or his wheelchair, and to get in and out of a car. She also supports him with getting on and off the toilet and getting in and out of the shower.

After Tiko lost his job, money has been tight at home. Tiko gets \$129 monthly allowance from the Fiji government’s Disability Allowance Scheme. Together with his wife’s small income, this wasn’t enough to pay for rent, so the family moved into special housing for low-income households.

The family’s new house is very small and a challenge for Tiko to move around in. The house has one bedroom, a kitchen and small bathroom connected by a narrow corridor. Tiko can only use his crutches inside because the doorways are too narrow for his wheelchair. Leaving the house is a challenge too. The local area is hilly, and Tiko requires support to push his wheelchair over uneven and steep paths.

“I asked the housing council to improve the footpaths and put in some ramps, but they haven’t promised anything. Decisions are made during the housing council meetings, but I don’t attend the meetings as there are many steps leading to the hall. I need assistance from someone who can lift me up the stairs.”

Tiko’s wife is his only support person, but she cannot support him all the time. “I must wait for her to get home from work. But she has other responsibilities. She takes the kids to school, goes shopping, and does the cooking and cleaning. Sometimes she is so tired she can’t support me—then I wait for her to rest.”

Tiko worries about his wife and wishes there were other supports available to his family. “The kids are too young, and our relatives live in a village in the hills, so they can rarely come and help. The neighbours are nice people, but I’m not comfortable asking them for help. I don’t want to burden them. The OPD said that you can pay personal assistants who come to your home, but we can’t afford this cost right now.”

### **Tiko’s continuum of support needs**

Layer 1: Support Services: Tiko requires additional mobility supports for personal, domestic activities and community activities (e.g. from support worker or neighbours) for when Tiko’s wife is unavailable.

Layer 2: Empowerment and Capacity Building Programs: The OPD can support raising awareness among neighbours and housing council members about the support needs of residents with disability and their families. Tiko can receive training on his rights from the OPD, information on accessible housing models and peer connection. Physiotherapy from the hospital may be able to assist Tiko in strengthening his leg and increasing his independence in transfers and mobility.

Layer 3: Accessible and Enabling Environments: Building accessible footpaths and installing wider doorframes and bathroom fittings to give Tiko more independence in the home and community. Income support to pay for additional supports and home modifications.

## Story 2 – Hina and Afiya, Fiji

Hina is 39-year-old Indo-Fijian woman. She is the main support person for Afiya, her 20-year-old daughter, who has an intellectual disability. Together they live with Hina’s elderly mother in a semi-urban area. Hina and Afiya moved from Suva after Hina’s mother became unwell and needed daily care. Afiya’s father stays in Suva for work. He sends money to Hina and visits once a month.

Afiya is not able to speak and communicates using body language and hand gestures that only her mother and father understand. Afiya does not need much support at home. She mostly needs support for activities outside the home to ensure she is safe, or when learning new skills.

Afiya used to attend a special school for children with disability in Suva where the teachers taught her to communicate by looking and pointing at pictures. This gave her the confidence to express herself to her parents. After they moved to the village, Afiya briefly attended an adult vocational school in a nearby town. The teachers didn’t know how to communicate with her, and the other students were not friendly to her, so she stopped attending the school.

Nowadays, Hina and Afiya mostly stay at home. Afiya helps with chores and looking after her grandmother, bringing her food and drink. She feels comfortable and safe at home with her family. Afiya gets nervous with other people, particularly strangers. She doesn’t have any friends.

When Hina walks to the local shops for supplies, Afiya goes with her. Hina asks the neighbours to look out for her mother when they are gone. Hina doesn’t like to leave Afiya at home alone. Some young men in the neighbourhood have made advances, and she is worried that Afiya can’t tell them to stop. Sometimes they gather outside the house and tease her, and then Hina shoos them away.

Hina wishes there was someone trustworthy to look after Afiya and grandma when she goes shopping. Someone who can communicate with Afiya, teach her new skills, and make her feel safe. She wishes someone would also speak to the neighbours to tell them to accept and value Afiya as an equal.

Now the vocational school is taking new students to learn crochet and sewing. Afiya wants to join but is scared about getting bullied again. Hina wishes the teachers took extra time to show Afiya how to sew in a way she understands. “Afiya can learn new skills when there is someone sitting side by side and showing her slowly. I want to the teachers to stop other students from teasing her. I would go with Afiya if I could, but I need to look after my mum.”

### **Hina’s and Afiya’s continuum of support needs**

Layer 1: Support Services: Afiya needs personal support to communicate with new people and learn new skills that build her confidence and task independence. An extra support person who is trustworthy and knows Afiya’s support needs to participate in community activities when Hina is busy. Additional in-home support for Hina’s mother or community-based respite options would enable Hina to provide more support to Afiya.

Layer 2: Empowerment and Capacity Building Programs: Learning vocational skills of her choice could empower Afiya and enable her to support household income. Afiya could learn these skills from teachers who use the inclusive communication and adjust learning activities according to her needs. Afiya may find spending time with other peers with disabilities empowering. Training and awareness raising from an OPD on how to provide supports could enable a circle of support to be formed around Afiya and her family.

Layer 3: Creating accessible and enabling environments: Afiya is harassed and bullied by young men in the community. Fear of strangers contributes to her social isolation. Awareness raising and behavioural change initiatives could be used to reduce stigma and harmful practices in the community. Teachers trained in inclusive education, including inclusive communication and learning adjustments.

## Story 3 – Mareoni and Alisi, Fiji

Mareoni is a 38-year-old iTaukei-Fijian woman who lives in an informal coastal settlement on the island of Viti Levu. Her brother and his family live nearby. She has three daughters who are 13, 15, and 17 years old. The eldest, Alisi, has cerebral palsy and a physical disability. One year ago, Mareoni’s husband died of diabetes. Now Mareoni and her other daughters are Alisi’s main supports.

For Alisi, having cerebral palsy means she has difficulty controlling her arms, legs and mouth. She needs support with almost all her daily activities. Mareoni helps her with feeding and drinking, getting in and out of bed, going to the toilet, getting dressed, and washing her body.

Although Alisi can take a few steps with assistance from someone, she mostly uses a wheelchair given to her by an OPD. She can use the wheelchair to move herself around the house. Outside, she needs someone to push the wheelchair for her. She does not have strength and control in her arms to push for longer distances or when the ground is uneven. Sometimes, the wheels get stuck in the sandy soil.

Alisi’s speech and communication is affected by her cerebral palsy. She can understand everything that people say to her, but it takes her a long time to say the words she wants to say. People who don’t know her well have difficulty understanding her, including extended family. Mareoni says her and Alisi’s sisters can understand her easily. “We translate so others understand her, including at the doctors.”

Mareoni says life is becoming harder in the coastal settlement. Soil erosion and pollution are making the mangrove trees sick. Now, some trees are dying, and the ocean is coming closer to the village.

In a storm, the water rises and the family must leave quickly to find shelter on higher ground. There is an evacuation centre at the school, but the road to get there is long and steep. Without a car, getting there is difficult for Alisi. Instead, Mareoni’s family goes to her brother’s house, which is easier to walk to.

In the last storm, Mareoni’s brother rushed to carry Alisi out on his shoulders. “Alisi was very upset and was screaming, but I couldn’t go to comfort her.” Mareoni explained that, in their culture, there are lines of respect around how Mareoni should speak and be close to her brother. At her brother’s house, Mareoni is asked to cook and do chores to help her sister-in-law. Without the wheelchair, Alisi lies on a bed on the floor.

Mareoni says the Red Cross have given her house’s location to the local Disaster Management Office. She was told emergency responders would come to assist with taking Alisi to the evacuation centre where they have food, blankets, beds, and wheelchairs—but this never happened. Mareoni worries that one day the water will come so quickly they won’t be able to escape in time.

### **Mareoni’s and Alisi’s continuum of supports**

Layer 1: Support Services: Alisi needs additional mobility and communication supports for personal, domestic and community activities, including for when Mareoni and Alisi’s sisters are unavailable and during emergency evacuations.

Layer 2: Empowerment and Capacity Building Programs: Alisi may benefit from Speech therapy to develop communication strategies and physiotherapy for improving mobility. Training for extended family and service providers (e.g. healthcare staff and emergency responders) in alternative communication techniques. Alisi may like to attend at her local OPD where she can receive training about her rights as a person with disability.

Layer 3: Creating accessible and enabling environments: Building wheelchair-accessible footpaths and home entrances (e.g. ramps). Emergency responders have a plan to evacuate Alisi and her family in a flood. Income support to pay for additional supports (e.g. ramp for house access).

## Story 4 – Filo, Tuvalu

Filo is a 35-year-old man from Tuvalu. He was born with a vision impairment and sees blurry shapes and shadows. Filo grew up on Vaitupu, an outer island, where he lived with his mother and father. When his parents passed away, he came to live in Funafuti with his aunty, uncle and their two adult children.

During the day, Filo stays home and does chores. He washes the dishes, cleans the floors, feeds the pigs, and sweeps the surroundings. Filo says working hard to keep things clean and tidy is good for his health and wellbeing. Filo's aunty, uncle and cousins work all day in the family laundry service in the front room of the house. Filo says, "It's very important they run the business because it supports the family."

Filo can easily do his chores, so long as the house is free of mess and clutter. He knows the floorplan from memory and uses his hands and a stick to feel around furniture and objects. The family keeps the pathways clear so Filo can walk easily without falling over.

Going outside the home is difficult for Filo, so he mostly stays at home. The front door leads out onto a busy road. In peak hour, there are many cars and motorcycles driving past. Once, Filo was hit by a motorcycle when crossing the road. He was not injured, but since then he is scared to walk outside by himself. Now he only goes outside with his aunty, uncle or cousins—they support him by holding his hand, watching out for traffic, and steering him away from objects and tripping hazards.

Filo works hard in other ways too. He rolls pandanus leaves into cigarettes to sell at the shops. His cousins help him collect the leaves. Before the accident, he used to walk to the shops by himself. Now he waits until his cousins are free to go with him, but they are often too busy. Filo says his cousin once took the cigarettes to the shops but kept some of the money for themselves. These days, Filo mostly sells to passersby near his home. "If I could get to the shops more often, I could sell more cigarettes, buy tobacco in bulk, and increase my earnings. But I don't have anyone to go with me at the moment."

Filo says staying at home all day is bad for his health and fitness. He would like to do some exercise and join in sports with other people in his community. He has heard there is a treadmill at the physiotherapy clinic that he could use to build his fitness and confidence in walking but it is difficult for him to get there. "I wish someone could walk with me so I can exercise and get to the clinic during the day." But Filo is shy to ask others for support when his family are busy. "I don't want to burden my friends or neighbours. I just wait for my family to become available."

### Filo's continuum of supports

Layer 1: Support Services: Filo requires additional mobility and transport supports for leaving the home to ensure access to health services, income generation and recreational activities in the community. Engaging friends and neighbours to create a circle of support with his family can increase access to supports and provide respite.

Layer 2: Empowerment and Capacity Building Programs: Filo wants to access physiotherapy for building fitness and confidence with walking and doing exercise. The OPD may support Filo to attend national forums when he can share the needs and interests of people with disabilities.

Layer 3: Creating Accessible and Enabling Environments: Building safe and accessible sidewalks and pedestrian crossings for people with vision impairments including near shops and public amenities.

## Story 5 – Lagi and Fiafia, Tuvalu

Lagi is a 46-years-old woman living in Funafuti in Tuvalu. She is the main support person for her daughter, Fiafia, who is 24 and has a cognitive and psychosocial disability. They live in a small house with Lagi's sister and two young nieces. Lagi's husband works in Australia in the seasonal worker program.

Fiafia started having depression and anxiety when she was 22. Lagi says this started after she broke up with her boyfriend. "He was abusive", says Lagi. "He hit her many times. One time so bad she fell and hit her head on the floor. After that, she had trouble concentrating and remembering.

Lagi worked as a nurse at the hospital but stopped when Fiafia became unwell. Fiafia needs support to stay focused on tasks. Lagi stands by her side to give her encouragement and reminds her about what to do. She usually helps Fiafia get started on a task and prompts her if she gets stuck.

"I am a very busy lady. I supervise Fiafia with making meals, taking a shower—those sorts of things. I also look after my nieces when my sister is working. She does food catering. Sometimes my sister looks after Lagi when she isn't working, but if Lagi starts getting upset, she asks me to take over."

Fiafia finds it hard to control her emotions. Sometimes she gets really upset. "If we can't help her to feel calm, we call the police to come and take her to the doctor. We are scared she will hurt herself." The police come and put her in a prison cell and wait for the doctor to visit.

Lagi wishes she had better strategies for giving Fiafia emotional support. "I don't know what to do when she gets upset. I want to learn how to calm her down to avoid calling the police." There are no mental health or psychosocial support providers in Tuvalu that can suggest strategies for supporting Fiafia. Lagi watches YouTube videos to learn communication strategies, but they are mostly in English and hard to understand. "I want someone who knows about these strategies to teach us properly."

Lagi wishes she could employ a personal assistant to take over supporting Fiafia when she need a break. "Even just for a couple of days a week. Then I could get some rest, do some gardening, and help at the island community (fenua) events. I could work a few days at the hospital to earn some more money."

"I heard of people from Fiji who come to Tuvalu to support people in their homes. I would pay someone I can trust who gets along with Fiafia and has the skills to help her learn to those daily tasks. I want her to build her independence so she can take care of herself and get back to helping the community too."

### **Lagi's and Fiafia's continuum of supports**

Layer 1: Support Services: Fiafia requires daily supports for personal and domestic activities and emotional regulation. Lagi needs additional support to assist in providing day to day support for Fiafia and domestic duties. Lagi and Fiafia may benefit from peer support and community-based respite support.

Layer 2: Empowerment and Capacity Building Programs: Access to training on trauma-sensitive mental health supports for family members of people with psychosocial disability and first responders to mental health crises would help ensure supports do no harm to Fiafia. Fiafia may benefit from empowerment and support of a peer-peer support group. Access to on-call community-based mental health and psychosocial supports would ensure the safety of Fiafia and family members in a crisis. Specialist health services that provide diagnosis, treatment and therapy for mental health conditions and cognitive impairments related to brain injuries and trauma may be useful.

Layer 3: Creating accessible and enabling environments: Social and behavioural change programmes addressing gender-based violence to contribute to reductions in violence against women and girls, including family violence towards women with disability. OPDs may be able to advocate for inclusion of people with psychosocial disability in policy and planning.

## Story 6 – Sila and Tupulaga, Tuvalu

Sila is a 34-year-old Tuvaluan woman with a physical impairment. She recently moved from Niutao, an outer island, to Funafuti for work and lives there with her sister's family. Her husband lives in Niutao with their two 8-year-old children who are twin boys. One of the twins, called Tupulaga, has autism.

Sila found out she has multiple sclerosis after she started having difficulties walking. The pain comes and goes, and walking is painful. To make moving around easier, Sila uses a wheelchair, which she got from Fiji with the help of Fusi Alofa Association, Tuvalu's organisation of people with disability.

Sila works in the Tuvalu government. To get to her office, she uses Fusi Alofa's free transportation service—an accessible van with ramp access and extra space for wheelchairs.

The van is Sila's only way to get to work. If it is raining and there is flooding on the roads, the van doesn't come at all. Sometimes the van breaks down. "When this happens," she says, "I stay home."

Sila travels to Niutao to visit her family every few months. She wants to go more often but travelling there is difficult. When the ferry reaches Niutao she can't get into the smaller boat that takes people to shore. Instead, she is lowered down in a box with the cargo. She says this makes her feel embarrassed and humiliated: "It's like I am freight, not a person."

Sila earns enough money to pay for a babysitter—a 20-year-old woman from Fiji—who looks after the Tupulaga during the daytime when her husband is out working in the fisheries. Tupulaga has difficulties with learning to do things for himself and has communication difficulties. The babysitter prepares food for them. They play and watch TV together and sometimes go to the beach. Tupulaga likes watching the waves. When the waves crash, he shouts and flaps his hands with excitement.

Some people in the village think Tupulaga is different and stare at him. Tupulaga is old enough to go to primary school like his brother, but Sila is scared he will be bullied and won't get the right support: "It's better he stays home with the babysitter." Niutao does not have an inclusive education centre like in Funafuti. Sila worries Tupulaga is not learning and won't be able to work when he gets older.

Sila says life in Tuvalu is hard and worries about the family's future. She wants to apply for visas to move to Australia under the Falepili Treaty. Sila heard she could access different services for people with disability. "If we move to Australia, I could get rehabilitation for my back. Tupulaga could go to a school. We could use the trains and buses to get around. All those things that we don't have here."

### **Sila's and Tupulaga's continuum of supports**

Layer 1: Support Services: Sila requires accessible car transportation with wheelchair access so she can get to work. Tupulaga requires support for self-care activities, understanding learning activities, and social interaction at school.

Layer 2: Empowerment and Capacity Building Programs: Tupulaga requires access to teachers who are trained and know how to support students with autism with adapted learning tasks and materials. Sila could benefit from access to specialist health care to obtain information about how to manage fluctuations in her disability, and strategies for managing her pain and energy.

Layer 3: Creating Accessible and Enabling Environments: Sila requires modified ramps, walkways and seating arrangements so she can access the passenger ferry using her wheelchair. A community social and behavioural change programme addressing bullying of children with disability in communities and in schools would reduce the impact of stigma as a barrier to Tupulaga's learning.

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**Nossal Institute 2025**

