

# Human Rights Education for People with Disabilities in Samoa

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**I** WAS BORN DEAF IN RURAL SAVAI'I IN SAMOA. There were no accessibility services where I grew up, and I grew up without access to many important things.

When I was four years old, I started attending school however there were no sign language interpreters in my village. I had never even seen someone use sign language.

Growing up with no access to sign language meant that I was unable to communicate effectively with my teachers, explain to a doctor when I felt sick, or understand what the pastor was saying in church every Sunday.

I felt very isolated and could not keep up with other kids my age. I did not know what was happening in my community and I always got bad grades in school because I never understood what the teacher was saying.

It was not until I was much older that I realized I had the same rights as people without disabilities. And when I was supported with a sign language interpreter, I could do the same things as everyone else.

My experience since childhood as a person with disability inspired me to stand up and advocate for the realization of human rights of people with disabilities. I do not want the future generations of people with disabilities to face what I experienced when I was growing up.

When I was 11, I moved to Samoa's capital city Apia so that I could attend an inclusive education school. It was here that I learned sign language and was able to start learning how to read and write. I learned of organizations such as Nuanua O Le Alofa, Samoa's national advocacy organization for persons with disabilities and started to learn about human rights. Unfortunately, circumstance meant I was unable to finish my education, however my time in Apia taught me so much about what was possible.

## **Situation of People with Disabilities in Samoa**

Approximately 1.7 million people in the Pacific are living with some form of disability. The Pacific Disability Forum has documented that people with

disabilities in the Pacific experience many cultural and physical barriers to full participation as well as lack of access to communities, education and the workplace.

In Samoa, one hundred ninety people cannot hear at all or have a lot of difficulty. The majority of deaf and hard of hearing communities are located in rural areas of Upolu and Savai'i Islands.<sup>1</sup>

According to data from the Samoan Bureau of Statistics, of the population with disabilities in Samoa, 9.6 percent have never been to school, compared to 1.7 percent of those without disabilities. Only 4 percent of the population with disabilities are formally employed. These statistics highlight the exclusion rates of persons with disabilities in Samoa.

A study jointly conducted in 2021 by the United Nations Population Fund, Women Enabled International and Pacific Disability Forum reveals that people with disabilities suffering from “[I]nformal deprivations of legal capacity are commonplace in Samoa.”<sup>2</sup>

Young persons with disabilities in Samoa are generally entitled to equal recognition under the law. However, in practice many experience a denial of their right to make decisions for themselves, particularly in healthcare settings. The study lists the common ways this occurs in Samoa:<sup>3</sup>

- Harmful stereotyping by both service providers and family members that a person with a disability cannot make a decision independently;
- Services that rely on third parties (often family members or OPDs [organizations for persons with disabilities] to provide interpretation or other accessibility measures, which restricts the ability of the person with the disability to make decisions independently;
- Lack of clear legal and policy supports and safeguards to enable a person with a disability to make their own decisions through supported-decision making mechanisms and to challenge a denial of their right to make a decision for themselves;
- Disempowerment of persons with disabilities, which prevents people from understanding and advocating for their right to make an independent decision; and
- Lack of support services and social protection schemes for people with disabilities and their families, which leads to people with disabilities being economically dependent on their family.

## **Samoa National Policy for Persons with Disabilities**

The Samoan government's National Policy for Persons with Disabilities 2021-2031 (adopted in July 2021) states in its preamble the situation and the policy response:<sup>4</sup>

Disability is a human condition, those living with disabilities are members of our community and society. Inclusivity is about equal opportunities for all; everyone participating and contributing to the development process. Yet, persons with disabilities are the most marginalised members of society, often excluded from the decision-making processes that directly affect their lives. They face many obstacles that prevent or limit their capabilities to become part of society and contribute effectively to the development of the communities and nation in which they live.

This National Policy for Persons with Disabilities aims to provide a national disability-inclusive development agenda for Samoa, for the next 10 years.

The National Policy has advocacy and awareness as expected outcome:<sup>5</sup>

### **Advocacy and awareness**

- Recognising, promoting and enhancing the rights of persons of disabilities, and addressing negative stereotyping and discrimination against them, including the many disparities between persons with disabilities and those without, required a shared understanding about those rights, their significance to persons with disabilities, and how persons with disabilities rights and disability-inclusion should be addressed through policies, systems and practices of service organisations such as ministries, schools, employers, and businesses. Better awareness of services that exist and those not yet exist for persons with disabilities is needed.

On the other hand, one of the objectives of the Disability Inclusive Development Agenda of the National Policy is to increase “awareness about the rights and needs of persons with disabilities.”<sup>6</sup>

This objective is meant to be achieved through programs and activities such as the following:

1. Research and awareness on the prevalence and characteristics of disability, as well as existing gaps on disability-inclusion. This includes a research to establish current levels of awareness and understanding about the needs and rights of persons with disabilities in Samoa in accordance with the CRPD.
2. Programs and activities aimed at empowering persons with disabilities to promote and advocate for their rights, issues and needs.
3. Awareness programs on the challenges and issues faced by persons with disabilities including barriers preventing and limiting their participation in society.

While these documents demonstrate a high-level commitment of the Government of Samoa to see the realization of human rights for persons with disabilities in Samoa, disability advocates have raised concerns that these documents did not receive proper consultation with the disability community. I myself was part of the consultative process for the National Policy and despite being part of a group that made a submission to the Ministry of Women, Community and Social Development on our concerns about the draft policy, we did not see our feedback reflected in the final result nor have the opportunity to meaningfully engage with the Ministry during the policy's development.

### **Deaf Association of Samoa**

In 2017, I was part of a founding group that established the Deaf Association of Samoa. Prior to 2017, while support services and disability advocacy organizations had existed for some time, Deaf people had never had the opportunity to meaningfully lead advocacy efforts on behalf of ourselves. We had found that other, non-deaf people had often made decisions on what they deemed was best for us and we wanted to change that.

Today, the Deaf Association of Samoa remains the only organization that has a majority deaf or hard of hearing governance board.

Having experienced many years of marginalization by both the wider community, and even accessibility services run by people without disabili-

ties, we wanted to establish an organization where our own life experiences, Deaf culture and ownership of our own language were respected. I was on the first Board of the Association, and in 2019 was voted in as the Vice President. I stepped down in 2020 so that I could take up a position as one of the first paid staff members of the Association.

The Mission of the Association is to advocate for equal opportunities and full participation for persons who are Deaf and hard of hearing in all aspects of Samoan society.

The Association's Strategic Plan (2020-2025) vision is for "An inclusive Samoa that is responsive and ensures the promotion and protection of the rights of persons who are Deaf and hard of hearing" and has six key outcomes:

Outcome 1: The Samoan Government respects, protects and fulfills the rights of persons who are Deaf and hard of hearing.

Outcome 2: Mainstream the provision of sign language and gesture translations throughout government, non-government and community organizations to ensure accessible information and communication for all Deaf people.

Outcome 3: Ensure access to inclusive and accessible services across all sectors including but not limited to health, education, employment and church.

Outcome 4: Support the provision of accessible and inclusive public transport across all of Samoa.

Outcome 5: Advocate for translation and signage to achieve an accessible and inclusive physical environment for Samoa.

Outcome 6: A high performing and accountable Association.

The Association's board, staff and members continue to need to work to receive respect from the wider community, many of whom still believe that Deaf people do not have the capacity to lead the development and realization of our language and culture.

I cannot speak further on this issue without acknowledging the important work and support of Nuanua O Le Alofa. It is the leading disability advocacy organization in Samoa and was established in 2001.<sup>7</sup> It was the first organization in Samoa to be governed and led by persons with disabilities and was instrumental in advocating for the Samoan government's ratification of the Convention of the Rights of Persons with Disabilities in 2016.

The Association was able to be established due to the important work and support of Nuanua O Le Alofa which has paved much of the way for disability-led advocacy. The Association remains an affiliate of Nuanua O Le Alofa and continues to work in close collaboration with it to further the rights of persons with diverse disabilities in Samoa.

## **Human Rights Education**

Since we are not all born with equal access, it can be difficult to advocate for ourselves if we do not know what our rights are.

Learning from Nuanua O Le Alofa about my rights as a person with disabilities drastically changed my life. Further, seeing persons with disabilities such as Fa'atino Utumapu, General Manager of Nuanua O Le Alofa, travel the world to speak of the experiences of persons with disabilities in the Pacific and advocate for equity and equality greatly inspired me. I wanted to help share that knowledge with other people to empower them to stand up and advocate for their human rights.

Many interventions are needed to ensure that people with disabilities have equal and meaningful access in all aspects of society. One aspect is human rights education. Not only for people with disabilities to understand their own human rights, but also for people without disabilities, so they can understand that everyone has the same rights and they too can support the promotion of accessible and inclusive opportunities.

Through the Association, and working with the Deaf community in Samoa, I provide a range of deaf-led human rights education initiatives and advocates for the participation of Deaf and hearing-impaired persons in all aspects of society.

I took on a much larger role as an educator and teacher when I joined the Association as a staff member in 2020. I became the Project Officer of the Association and worked there until 2023 when I left to move to Fiji and study at the University of the South Pacific. Now, I continue to support the



Participants at the Deaf Association of Samoa's Annual Forum for Samoans who are Deaf, September 2021.<sup>8</sup> © Australian Humanitarian Partnership



(Above and next page) A sign language workshop led by facilitators including Maselina from Deaf Association of Samoa for children who are Deaf, 2021.





Association and work as a Disability Advocate. A large part of my job is working with the deaf community to understand their human rights in the context of the Convention on the Rights of Persons with Disabilities.



Maselina luta attending an international conference, advocating for disability inclusion in disaster risk reduction mechanisms, 2022

My role involves working closely with the members of the Deaf community to learn about their own human rights and support them to advocate for their rights to access education, employment and health services, to name a few.

I particularly enjoy working with young people with disabilities. I have found that youth with disabilities always want to engage in human rights education. We keep our programs activity-based and engaging and we are always asked to come back and run more programs.



Another component of my work involves providing advocacy and human rights education in national and regional contexts with mainstream organizations across a variety of sectors. We at the Association cannot achieve our mission and vision alone. We strive to develop enduring partnerships with stakeholders who are willing to recognize the importance of accessibility and inclusion and support the realization of rights for persons with disabilities.

## **Activities**

Human rights education is often the precursor to being able to advocate for the realization of rights of persons with disabilities.

In line with Outcome 2 of the Deaf Association of Samoa's Strategic Plan, when the COVID-19 pandemic was declared in March 2020, the Association worked hard to educate government stakeholders on the reality of the Deaf experience in the pandemic and highlight the importance of accessible information for all as detailed in Article 9 of the Convention on the Rights of Persons with Disabilities.

State of Emergency regulations changed on a weekly basis in the early



Maselina leading a discussion on marginalization of the Deaf community during the COVID-19 pandemic, 2021.

months of the pandemic, and the Association continued to receive reports from our members that due to the low literacy rates and inaccessible information, those who are deaf and hard of hearing struggled to know what rules were in place and often got in trouble for breaking those rules. In May 2020, together with Nuanua O Le Alofa, the Association was able to successfully advocate to the Samoan Prime Minister and Cabinet for the provision of sign language translation in the Prime Minister's weekly State of Emergency address. This was a

historical moment for Samoa, as it was the first time that Samoa had ever provided sign language translation at the national level.

While this was an important development and a successful advocacy achievement for the Association, we knew we had to take it further. With approximately 50 percent of our members not understanding formal sign language, we knew key messages were still not reaching many people. We then mobilized key members of our team to work from lockdown to create videos of gestures translation that were released on the Association's Facebook page, making the State of Emergency regulations accessible to all persons who were deaf and hard of hearing, no matter the level of education they had been able to attain.

Annually, the Association hosts a Members Forum in celebration of International Week of the Deaf. During the week, we bring up to one hundred members from across the country together to a single location for a week of connection, advocacy and education. The Forum organizers face the annual challenge of developing a program that is accessible to members aged between 10 – 55, some of whom have never attended a day of school.

The first session of the week is always about introduction. It is an emotional activity, with members helping each other learn how to spell their names and the villages they are from. Nerves are high, and everyone is tentatively watching each other, trying to gauge reactions.

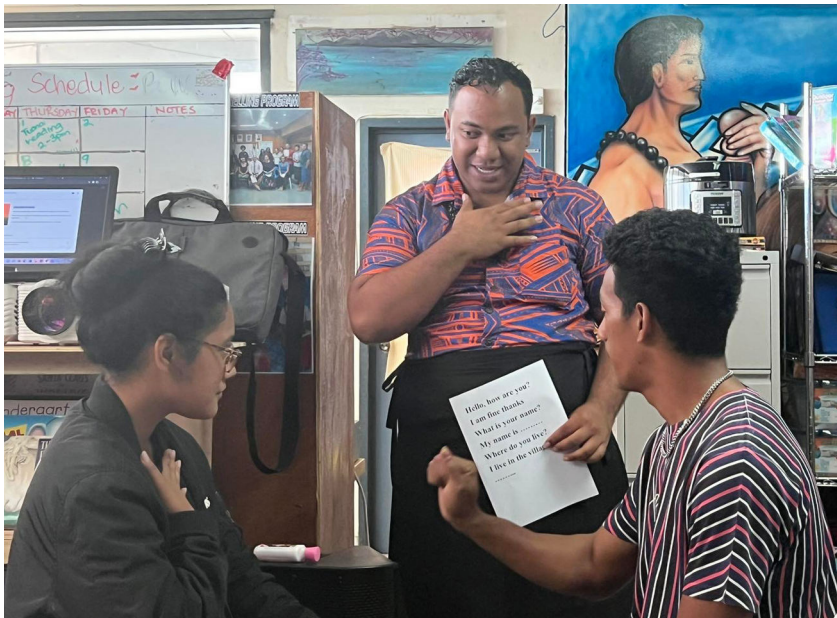
The program varies from year to year, sometimes including emergency evacuation simulations from Fire and Emergency services, visits to the Samoa Meteorology Services to learn about early warning systems and provide feedback on how to make multi-warning systems inclusive for persons who are Deaf and sessions with the electoral office, receiving support on registering to vote and understanding why casting your vote is important. A highlight in 2022 was when we were able to visit the Samoan Parliament, take a tour and learn all about our political system.

The week is filled with field trips to different places, where we facilitate two-way-learning, our members learning about different services and systems, and government and non-government agencies meeting with Deaf people, often for the first time, and listening to first-hand experience of their lived experience; and where they experience barriers in being able to access and participate in different aspects of Samoan society.

Throughout the course of the week, it is wonderful to see the confidence of our members grow, as they enter spaces for the first time, and

are supported to share their experience and advocate for their inclusion. Everyone supports each other and the week is filled with laughter and new experiences.

It is hard for everyone when we have to say goodbye at the end of the week. However, we consistently hear from families that their Deaf family members return home overjoyed and enthusiastic, ready to take on new challenges. Throughout the week we work to identify some of the hopes and dreams of our members, and use the following months to connect them with employment and education pathways, and include them in programs that align with their interests.



Activity during the 2022 International Week of the Deaf.

Our International Week of the Deaf program is the most anticipated week of the year for many of our members and they start contacting us to excitedly ask for plans many months in advance.

## **Challenges**

The Deaf Association of Samoa has made many important achievements since its establishment in 2017 as detailed above, however, we continue to face challenges.

Many challenges faced among Deaf community are related to the little educational, employment and decision-making opportunities. When we are invited to sit at the decision-making table at national and regional levels, we have to do significant work to compensate for the barriers we continue to experience due to lack of access to education. I find in my work that I must continue to advocate for not only the provision of sign language translation, but also to receive any key materials or potential questions prior to the meeting so that I have time to prepare with my interpreter. I often come to events where consideration of how the physical environment may impact my ability to see and communicate with my interpreter is not considered. It can be hard to have to consistently advocate for reasonable accommodations each and every day.

Additionally, there are organizations and individuals who still struggle to understand that just because they cannot hear me does not mean that I do not have thoughts, feelings and opinions. I find myself in situations where hearing people correct me on my use of my language or tell me that my perspective is not correct. At times I find that while I have been invited to an event, it does not mean that there is space and consideration to meaningfully hear from me. People who do not share my lived experience will sometimes speak with authority on the barriers they believe I experience or the support that I need. It is important for all non-disabled people to remember that while being an ally is incredibly important to the disability rights movement, they must make space to hear from disability advocates themselves.

### **Some Reflections**

I am proud to be a human rights educator because I am part of a movement that ensures that people with disabilities have equal access to their human rights.

I am really proud of the fact that through my work, I am able to ensure Deaf-led advocacy for the Deaf community.

Being a young Deaf woman from Savai'i, I get to speak throughout the country to members of the Deaf community and I can see the impact it has.

You cannot be what you cannot see. I hope that people with disabilities seeing me in spaces that traditionally do not include people with disabilities

will inspire the next generation of the Deaf community to understand their rights and see that they can be anything they want to be.

The big changes that I have seen have been at the individual and family levels. Working with families of young Deaf children in Savai'i, I see them realize that their child could grow up just like me to take on leadership roles and work to support their family.

Another exciting change has been seeing the increased confidence of Deaf women and men my own age who are realizing that access to inclusive education and employment opportunities is possible and that with knowledge of their human rights, they can advocate for opportunities in their own lives.

The world needs human rights education because we are not all born with equal access, and it can be difficult to advocate for ourselves if we do not know what our rights are. We need the support of the community, so that we can continue to fight and support the rights of those who are deaf in Samoa.

## **Endnotes**

1 Samoa Bureau of Statistics, Ministry of Women Community and Social Development, Pacific Community, and UNICEF Pacific. (2018), 2018 Samoa Disability Monograph-An Analysis of the 2016 Population and Housing Census, [www.spc.int/DigitalLibrary/Get/wb78s](http://www.spc.int/DigitalLibrary/Get/wb78s).

2 United Nations Population Fund, Women Enabled International, Pacific Disability Forum, Women and Young People with Disabilities in Samoa: Needs assessment of sexual and reproductive health and rights, gender-based violence, and access to essential services (2021), [https://pacific.unfpa.org/sites/default/files/pub-pdf/pwd\\_srh-gbv\\_needs\\_assessment\\_samoa\\_220422\\_highres.pdf](https://pacific.unfpa.org/sites/default/files/pub-pdf/pwd_srh-gbv_needs_assessment_samoa_220422_highres.pdf).

3 United Nations Population Fund, Women Enabled International, Pacific Disability Forum, *ibid.*, page 14.

4 National Policy for Persons with Disabilities 2021-2031, page 5, <https://mwcsd.gov.ws/wp-content/uploads/2024/03/National-Policy-for-Persons-with-Disability-2021-2031.pdf>.

5 *Ibid.*, page 9.

6 *Ibid.*, page 12.

7 Lemisio, A. T., Boodoosingh, R. and Utumapu, M. F. (2021), "Pivoting during a pandemic: a case study of a Samoan NGO," *Development in Practice*, DOI: 10.1080/09614524.2021.1993143.

8 Australian Humanitarian Partnership, <http://australianhumanitarianpartnership.org/field-stories/i-saw-videos-of-people-in-mask-and-people-dying-but-i-don't-know-what-it-means-supporting-samoas-deaf-communities-through-covid-19>.