

WOMEN AND YOUNG PEOPLE WITH DISABILITIES:

A needs assessment of sexual and reproductive health and rights, gender-based violence, and access to essential services

Samoa

2021



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Table of contents

List of acronyms	2
Executive summary	3
Summary of general recommendations	3
Summary of issue-specific recommendations	4
1 Introduction and methodology	5
2 Priority issues at the intersection of gender and disability	7
3 Findings: Overview of the situation in Samoa	9
4 General recommendations	13
5 Legal and policy barriers	14
5.1. Issue 1: Informal deprivations of legal capacity are commonplace in Samoa.	14
5.2. Issue 2: Access to justice is limited for people with disabilities in Samoa, particularly for women and young people experiencing GBV.	16
5.3. Issue 3: Referral pathways between SRH, GBV, and disability-service providers require strengthening.	17
6 Social and attitudinal barriers	18
6.1. Issue 1: Women and young persons with disabilities in Samoa experience ongoing stigma and discrimination.	18
6.2. Issue 2: Women and young people with intellectual disabilities in Samoa face unique forms of discrimination.	19
7 Physical barriers	21
7.1. Issue 1: Physical accessibility in Samoa, particularly telecommunication accessibility, requires ongoing investment and improvement.	21
8 Information and communication barriers	23
8.1. Issue 1: SRH and GBV awareness-raising information is often inaccessible in Samoa.	23
8.2. Issue 2: Information, education and communication materials at health facilities are generally inaccessible in Samoa.	25
8.3. Issue 3: People with disabilities usually do not have access to family life education in Samoa.	26
Endnotes	28

List of acronyms

CEDAW Committee	UN Committee on the Elimination of Discrimination against Women
CRPD	Convention of the Rights of Persons with Disabilities
CRPD Committee	UN Committee on the Rights of Persons with Disabilities
CSE	Comprehensive sexuality education
FLE	Family life education
GBV	Gender-based violence
IEC	Information, education and communication
LGBTIQ	Lesbian, Gay, Bisexual, Trans, Intersex and Queer
NGOs	Non-governmental organizations
NOLA	Nuanua O Le Alofa
OPDs	Organisations of persons with disabilities
PDF	Pacific Disability Forum
SFHA	Samoa Family Health Association
SRH	Sexual and reproductive health
SRHR	Sexual and reproductive health and rights
STIs	Sexually transmitted infections
SVSG	Samoa Victim Support Group
UNFPA	United Nations Population Fund
UNFPA Pacific	United Nations Population Fund – Pacific Sub-Regional Office
WEI	Women Enabled International

Executive summary

Women and young people with disabilities in Samoa experience a range of restrictions to accessing sexual and reproductive health (SRH) and gender-based violence (GBV) services on an equal basis with others and to realizing their rights to SRH legal capacity, and freedom from violence.

Barriers manifest in a multitude of ways including informal deprivations of legal capacity, encumbered access to justice, and weak referral pathways between SRH, GBV and disability-service providers. Moreover, women and young people with disabilities in Samoa experience pervasive stigma and discrimination, especially people with intellectual disabilities. Physical and telecommunication barriers further impede communicating with service providers and access to facilities. While inaccessible SRH and

GBV awareness raising programmes and information, education, and communication materials, along with the absence of disability-inclusive sexuality education, create even more entrenched barriers.

Nevertheless, Samoa's commitment to community and to realizing its duties under the Convention on the Rights of Persons with Disabilities (CRPD), along with the robust network of organisations of persons with disabilities (OPDs) in Samoa, means that Samoa is well positioned to tackle the barriers documented in this report. Through the implementation of the recommendations in this report, Samoa can serve as a model - in the Pacific region and globally - of comprehensive disability-inclusive SRH and GBV service provision.

Summary of general recommendations

This report proposes general recommendations for the State to dismantle the barriers documented in this report and to advance the fundamental rights of women and young people with disabilities living in Samoa. These recommendations can be summarized as follows:

- Pass comprehensive legislation harmonizing Samoan law with the CRPD.
- Ensure robust implementation of the *Samoa National Policy for Persons with Disabilities 2021-2031 (National Policy)*.
- Submit Samoa's State Party report to the Committee on the Rights of Persons with Disabilities.
- Invest resources to ensure that SRH and GBV services are accessible to people with diverse disabilities.
- Require all sexual and reproductive health and rights and GBV programming to be accessible and staffed by people trained on disability-inclusion.
- Ensure that people with disabilities are included in and considered in the development of any humanitarian emergency plan development, implementation, and monitoring.

Summary of issue-specific recommendations

This report also describes specific legal, policy, social, attitudinal, physical, information and communication barriers impacting SRH, legal capacity and GBV for women and young people with disabilities and includes a series of specific recommendations for addressing them. These recommendations can be summarized as follows:

Recommendations for addressing legal and policy barriers

- Pass legislation enumerating the right of people with disabilities to legal capacity, along with associated policies and programming.
- Invest in system-wide disability-inclusion capacity building for public and non-governmental providers in the healthcare and the justice sectors.
- Prioritize increasing accessibility in the healthcare and the justice sectors through increased sign language interpretation and accessibility mechanisms.
- Establish and fund effective referral pathways between key SRH, GBV, and disability-related service providers.

Recommendations for addressing social and attitudinal barriers

- Develop disability-specific values clarification trainings for a wide range of SRH and GBV service providers and for police and justice sector personnel.
- Create and expand rights-based awareness-raising programmes on disability rights and inclusion grounded in the CRPD framework and in consultation with OPDs.
- Address the under-diagnosis of intellectual disabilities and invest in early intervention and support services for people with disabilities and their families.

Recommendations for addressing physical barriers

- Incorporate accessibility for SRH and GBV services into all relevant initiatives and activities of the National Policy implementation.
- Develop a strategic plan and allocate funding for disability-accessible telecommunication, particularly relating to accessing SRH and GBV services.

Recommendations for addressing information and communication barriers

- Develop accessible SRH and GBV information, education, and communication materials for women and young people with disabilities.
- Establish a community health-liaison SRH programme for people with disabilities.
- Expand the disability-inclusivity of the Ministry of Women, Community and Social Development's Nation-Wide Gender-Based Violence Awareness Programme and the Village Family Safety Committees.
- Ensure broad consultation with a range of OPDs, disability service providers, and specialized schools in the development of Samoa's family life education programming.

1

Introduction and methodology

In 2020 the United Nations Population Fund Pacific Sub-Regional Office (UNFPA Pacific) engaged Women Enabled International (WEI) – in collaboration with the Pacific Disability Forum (PDF) and Nuanua O Le Alofa (NOLA) – to conduct needs assessment research to identify the barriers preventing women and young people with disabilities living in Samoa from fully realizing their sexual and reproductive health and rights (SRHR) and their rights to legal capacity and to be free of gender-based violence (GBV). This report summarizes research findings and priority recommendations for the State to eradicate those barriers and advance the fundamental rights of women and young people with disabilities.

Research for this report consisted of (1) **desk research**, reviewing the laws and policies of Samoa and available reports published by United Nations (UN) agencies, human rights monitoring bodies, and non-governmental organizations (NGOs); (2) **interviews with key stakeholders**, including local Organisations of Persons with Disabilities (OPDs), organizations providing sexual and reproductive health (SRH) services, GBV services, emergency services, non-profit umbrella organizations, and UN agencies working in country; and (3) **focus group discussions and interviews with women and young people with disabilities**. The focus group discussions and interviews were conducted by a local consultant with assistance from PDF and NOLA. PDF is a partnership of Pacific organisations of and for persons with disabilities. NOLA is a Samoan organisation set up by people with disabilities to advocate for their rights and equal opportunities. The original methodology conceived for this research involved WEI field visits to Samoa to conduct stakeholder interviews, focus groups, and individual interviews in-person, along with site visits to verify information acquired through these interviews. However, due to the COVID-19 pandemic and global restrictions on travel, WEI was unable to travel to Samoa. Consequently, WEI has relied on the veracity of the information collected by Ms.

Utumapu-Utailesolo and where possible has sought to cross-check information with other interviewees or online research whenever possible.

Key stakeholders were identified through the desk research and consultations with UNFPA Pacific and NOLA. Due to travel restrictions imposed by COVID-19, stakeholder interviews were conducted remotely by WEI staff and legal interns and by student attorneys with the Cardozo Law School’s Human Rights and Atrocity Prevention Clinic via Zoom, Skype, or in writing (depending on the platform preferred by the stakeholder). WEI conducted interviews with PDF; Pacific Community (SPC) Human Rights and Social Development Division; the Ministry of Women, Community and Social Development; UNFPA Pacific; UN Women – Samoa Country Office; Office of the Ombudsman – Samoa National Human Rights Institution; NOLA; Samoa Victim Support Group; Samoa Family Health Association; SUNGO Samoa; and Samoa Red Cross Society. Attempts to secure stakeholder interviews with the following stakeholders were unsuccessful: the Ministry of Health; Samoa Law Reform Commission; and SENESE Inclusive Education.

Focus group discussions and interviews were conducted by Faaolo Utumapu-Utailesolo, an independent consultant with expertise on gender and disability recommended by PDF, with assistance from PDF and NOLA. The women and young people invited to participate in the focus groups and interviews were identified by Ms. Utumapu-Utailesolo with the assistance of NOLA and PDF. Participants were selected to reflect a diversity of disabilities, ages, and locations (urban and rural). Focus group participants were invited to participate in an individual interview following the focus group to share further information in private. Interviews took place with those who volunteered and provided informed consent to be interviewed alone or with the assistance of a support person/interpreter (with the consent of the interviewee).

Five focus groups with 32 people with disabilities were conducted: one with women with diverse disabilities in rural Savaii; one with women who are Deaf or hearing-impaired in Apia; one with women who are blind and/or have physical disabilities in Apia; one with women with intellectual disabilities in Apia; and one with young men with diverse disabilities in Apia. Individual interviews with focus group participants were conducted with 21 people with disabilities. Female participants ages ranged from 18 to 54. Young male participants ages ranged from 19 to 23.

Focus group and interview participants were informed that the research being conducted was critical to better understanding the experiences that women and young people with disabilities have in their communities and in accessing SRH services, and information, as well as GBV services. Participants were informed that researchers sought to learn about their opinion and experience and that there were no right or wrong answers. After the participants were invited to ask questions, their consent to carry out the focus group or individual interview was sought. Informed consent for both the focus group and individual interviews was obtained by: explaining the reason for the research and how the information would be used; outlining the types of questions in the interview, highlighting to the participant that some questions were quite personal; assuring the participant of the confidentiality of their name and

any details that would lead to their identification; and informing the participant that they could decline to participate, skip questions, and stop the interview at any time.

Samoan was the primary language used in the focus groups and interviews. Notes were transcribed from Samoan to English. Quotes used throughout this document have been translated into English from Samoan. Due to challenges of translations, quotes are as close to the original language communicated by the respondent as possible but are not verbatim. Nevertheless, they accurately capture the substance and information conveyed. They are included with quote marks to convey that the text has been taken directly from the interview notes. Pseudonym initials are used to identify the speaker and protect their confidentiality.

Acknowledged gaps in the current research include interviews with the Ministry of Health, Ministry of Justice and Courts Administration, and the Ministry of Communications and Information Technology. Additionally, while the current focus groups and stakeholder interviews reflect a broad diversity of disabilities and service providers, people with psychosocial disabilities are not fully represented nor are service providers who provide services for people with psychosocial disabilities such as Goshen Trust Mental Health Services Samoa.

2 Priority issues at the intersection of gender and disability

This needs assessment research focuses on three priority issues impacting human rights at the intersection of gender and disability: SRHR, legal capacity, and GBV. This section provides a brief overview of these issue areas globally and how gender and disability intersect to prevent women and young people with disabilities around the world from fully realizing their fundamental rights with respect to these issues. Additionally, this section summarizes the research findings relating to the impact of COVID-19 on these human rights areas.

Sexual and reproductive health: Reproductive health refers to the “state of complete physical, mental and social well-being, not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people can have a satisfying and safe sex life and that they have the capacity to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are: the rights of men and women to be informed, have access to safe, effective, affordable, and acceptable methods of family planning, including methods for regulation of fertility, which are not against the law, and the right of access to appropriate healthcare services to enable women to have a safe pregnancy and childbirth and provide couples with the best chance of having a healthy infant.”¹ Sexual health, which is a component of reproductive rights, comprises of “the enhancement of life and personal relations, not merely counselling and care related to reproduction and sexually transmitted infections. It refers to the integration of the somatic, emotional, intellectual and social aspects of sexual being in ways that are positively enriching and that enhance personality, communication and love.”²

Women and young people with disabilities have the same sexual and reproductive health rights as people without disabilities,³ and they are just as likely to be sexually active as their peers without disabilities despite inaccurate stereotypical views to the contrary. Accordingly, they have the same SRH needs as women and young people without disabilities. Due to multiple and intersecting forms of discrimination on the basis of gender and disability—such as harmful stereotypes that people with disabilities do not have sex or are incapable of becoming parents—women and young people with disabilities face unique and pervasive barriers to accessing essential SRH services.

Legal capacity: Legal capacity is defined as “the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency).”⁴ Legal standing and agency entitles a person to the full protection of their rights without state inference, and allows a person to engage in, create, modify, or end legal relationships.⁵ In the SRH context, this might take the form of the right to consent to a medical procedure and withdraw that consent upon learning further information; the exercise of this right for persons with and without disabilities is often referred to as the right to provide informed consent.⁶

Unfortunately, due to both gender and disability stereotyping, women with disabilities are often deemed incompetent or unreliable when making decisions or entering into a legal relationship.⁷ As a result, they are frequently subjected to substituted decision-making systems. In these systems, such as guardianship regimes, someone other than the person with the disability can be legally authorized to make legally binding decisions that impact that person’s life.⁸ Often there are limited safeguards in place for the person with a disability to challenge the loss of their legal capacity.

In countries with and without substitute decision-making regimes, people with disabilities also regularly experience substitute decision-making on an informal basis. Informal substitute decision-making occurs when a person other than the individual with the disability is permitted to make a decision for the person with the disability without any formal authorization to make such a decision.⁹ An example of an informal deprivation of legal capacity is an adult with a disability whose parent is asked to consent to a medical procedure or medication instead of the adult with the disability. Common informal substitute decision-makers include spouses, family members, or support persons. Informal deprivations of legal capacity are particularly insidious because of the lack of procedures and safeguards in place to protect the person with the disability.

The alternative to a substituted decision-making system - both formal and informal - is a supported decision-making system.¹⁰ Supported decision-making programming enables all people with disabilities, regardless of their impairment, to be able to understand the pertinent information required to make an informed decision and to access the assistance they require to make a decision.¹¹

Gender-based violence: GBV are acts “perpetrated against a person’s will and that is based on socially ascribed (i.e. gender) differences between males and females. The term ‘gender-based violence’ is primarily used to underscore the fact that structural, gender-based power differentials between males and females around the world place females at risk for multiple forms of violence. As agreed in the *Declaration on the Elimination of Violence against Women (1993)*, this includes acts that inflict physical, mental or sexual harm or suffering, threats of such acts, coercion and other deprivations of liberty, whether occurring in public or in private life. The term is also used by some to describe some forms of sexual violence against males or targeted violence against LGBTIQ populations.”¹² GBV can be perpetrated by intimate partners, family members, medical providers, educators, or employers and can take many forms, such as physical, emotional, sexual, and economic.¹³

Women with disabilities make up approximately one-fifth of the world’s population of women and are two or three times more likely to experience certain types of GBV.¹⁴ Despite the large number of women with disabilities affected, most laws and policies on GBV do not address the specific concerns of girls and women with disabilities.¹⁵ The lack of disability-specific legal protections, coupled with inadequate accessibility mechanisms and lack of training across protective and preventative services and the justice sector—frequently prevent GBV survivors with disabilities from reporting the violence, seeking essential GBV services, and accessing justice.

3

Findings: Overview of the situation in Samoa

Women and young people¹⁶ with disabilities in Samoa experience similar barriers to accessing SRH and GBV information and services on an equal basis with others as do people with disabilities globally.¹⁷ The Samoan cultural context of Fa’aSamoa¹⁸—the Samoan way of life—coupled with the developing policy context in Samoa presents both unique manifestations of these barriers and opportunities to improve access. With a robust network of OPDs and a government and network of NGOs committed to disability-inclusion, meaningful improvements in access to disability-inclusive SRH and GBV information and services in Samoa is both possible and probable.

3.1. Country context

Fa’aSamoa principles and values inform the experiences of and policy towards people with disabilities in Samoa. The community values of Fa’aSamoa contribute to the support and acceptance many Samoans with disabilities experience in their families and villages. However, the Fa’aSamoa emphasis on community can also contribute to the perception of people with disabilities as community dependents rather than independent individuals capable of making their own decisions.¹⁹ Moreover, because one cannot be separated from one’s family and community, empowerment programmes for people with disabilities without concurrent programmes for family and community members, have limited effectiveness. Additionally, common stereotypes about people with disabilities – for example, that people are born with disabilities are a result of a curse²⁰ or that women with disabilities cannot care for their children²¹ – present barriers to acceptance of people with disabilities as full and equal rights-holders. Gender inequality and entrenched cultural gender-roles also persist in Samoa and impact women and young people with disabilities and their access to SRH and GBV services.²²

According to the 2016 census data using the Washington Group short set of questions, one in every fifty persons in Samoa has some type of disability,²³ which is significantly below the global average.²⁴ Disability prevalence among females is slightly higher than males - 2.2% and 1.9% respectively.²⁵ Rural areas in Samoa report a higher disability prevalence (2.1%) compared to urban areas (1.5%).²⁶ According to the data, visual impairments are the most common disability in Samoa, followed by mobility, memory, and hearing and cognition related impairments.²⁷ Census respondents with mobility impairments reported experiencing the highest level of difficulty in their daily lives.²⁸

Samoa is internationally, regionally, and domestically obligated to ensure that people with disabilities in Samoa are entitled to full realization of all their human rights and fundamental freedoms without discrimination, including their sexual and reproductive health and rights and freedom from violence. Samoa ratified the Convention on the Rights of Persons with Disabilities (CRPD) in 2016²⁹ and the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW) in 1992,³⁰ among other relevant international human rights treaties. Regionally, Samoa has committed to adopting the Incheon Strategy to “Make the Right Real” for Persons with Disabilities in Asia and the Pacific, building upon their previous commitments as part of the Biwako Millennium Framework for Action and Biwako Plus Five towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific.³¹

Since 2016, steady progress in advancing disability rights has been made in Samoa through policies and investment in the Samoan disability community. A *National Policy for Persons with Disabilities 2021-2031* was launched in July 2021.³² It includes two notable strategic outcomes for tackling the barriers to SRH and GBV services experienced by women and young people with disabilities in Samoa:

- **Strategic Outcome 1:** Increased awareness about the rights and needs of persons with disabilities, Subsection 6: Awareness raising and communications materials and resources on the additional challenges faced by women and girls with disabilities and strategies to ensure their participation in decision making at all levels.³³
- Strengthened provisions of support, health services and assistive devices, Subsections 11-12:
 - (11) Strengthen SRH education also through family life education and other community education and awareness programmes.
 - (12) Improve access to SRH and justice services including all other needed public services for persons with disabilities.³⁴

According to the policy, the State will also promote the full harmonization of Samoan laws with the CRPD, including by exploring the “possibility of developing a Disability Bill for Samoa to address existing gaps with disability-inclusion.”³⁵ In the past, there has been consultations and drafts of a comprehensive piece of legislation to align Samoan law with the duties enumerated in the CRPD, but they have stalled.³⁶

The impact and effectiveness of the *National Policy for Persons with Disabilities 2021-2031* will depend on commitment by the Samoan government to its full implementation, including robust consultations with OPDs and meaningful enumeration and financial investment in their role, and full harmonization of Samoan laws with the CRPD.

3.2. Sexual and reproductive health

Samoa is dedicated to realizing the sexual and reproductive health and rights of all Samoans and has committed to upholding these rights internationally and regionally through the Moana Declaration 2013 and the Pacific Sexual Health and Well-being Shared Agenda 2015-2019.³⁷ Access to SRH services for women and young people with disabilities is impacted by the broader cultural context of Samoa being a religious country with entrenched gender roles,³⁸ along with the disability-related barriers that exist. Accordingly, the *National Policy for Persons with Disabilities 2021-2031* recognizes that Samoan women and girls with disabilities are substantially disadvantaged when it comes to accessing SRH, which is addressed through Strategic Outcome 3.³⁹ The *National Policy on Gender Equality & Rights of Women & Girls 2021-2031* also aims at prioritizing health needs of women and girls with disabilities.⁴⁰

In general, Samoan “women with disabilities experience lower socio-economic status, higher rate of poverty, lower employment rate, have less education and are less likely to access quality health care compared to [women without disabilities].”⁴¹ Census data on women with disabilities’ reproductive health shows that Samoan women with disabilities give birth earlier than their peers without disabilities.⁴² Nevertheless, over time women without disabilities give birth to more children.⁴³ Samoan women with disabilities are also less likely to be married than their peers without disabilities – two out of ten women with disabilities are married as compared with six out of ten women without disabilities - and are also more likely to be widowed, divorced, or separated.⁴⁴ Data also indicates that women with disabilities are less likely to be married than men with disabilities.⁴⁵

Currently, Samoan people with disabilities primarily access SRH services through private and public health facilities, mobile services, and secondary health facilities overseen by the Ministry of Health. Samoa Family Health Association (SFHA) is the primary non-governmental SRH service provider. According to the women and young people with disabilities interviewed, most people with disabilities receive their SRH

information through a variety of sources but primarily through family members, OPD programming, and on occasion through education programming.⁴⁶ With the support of the SFHA, NOLA offers SRH trainings for people with disabilities, which are an essential source of sexuality education for adult women and young people of all ages and disabilities.⁴⁷ Moreover, NOLA provides support for SFHA and women and young people with disabilities seeking services, including by providing interpretation services, referrals, and other accessibility mechanisms that are essential to enable people with disabilities to seek SRH services.⁴⁸ While SRH services in Samoa are technically accessible to people with disabilities, many women and young people with disabilities experience sometimes insurmountable barriers to accessing services independently and further investment is required to ensure comprehensive access to SRH services for people with diverse disabilities.

3.3. Legal capacity

Samoa does not have a formal legal guardianship system that deprives people with disabilities of their legal capacity to make independent decisions. The two exceptions to this relate to administrative and judicial procedures to declare a person mentally incapacitated and requiring inpatient treatment under the Mental Health Act 2007⁴⁹ and unfit to serve as a witness under the Evidence Act 2015.⁵⁰ However, according to focus group and interview participants informal deprivations of legal capacity are commonplace in a variety of settings, including in the context of SRH services.⁵¹ The *National Policy for Persons with Disabilities 2021-2031* does not comprehensively address formal or informal deprivations of legal capacity.

“ Women without disabilities, they can talk to doctors. But us with disabilities, [doctors] do not often talk to us.”
–Deaf woman, age 23.⁵²

3.4. Gender-based violence

GBV rates are high in Samoa and people with disabilities are especially at risk of experiencing GBV.⁵³ For example, in studies conducted by the Ministry of Women, Community and Social Development over 85% of female respondents with disabilities reported experiencing physical violence.⁵⁴ There is limited disaggregated data on Samoan women with disabilities experiences with GBV.⁵⁵ However, one study found that 100% of Samoan women with disabilities surveyed experienced some form of violence or abuse and that 60% of those women had chosen not to report the violence they had experienced primarily because of fear.⁵⁶ Another survey of women with disabilities done by the Rollout of Ending Violence against Women and Girls with Disabilities in the Pacific found that 80% of women surveyed did not obtain healthcare for the violence they experienced due to both fear and inaccessibility of services.⁵⁷ Furthermore, women and young people with disabilities experience high levels of family violence, consistent with the findings of the *National Public Inquiry into Family Violence in Samoa* (2018).⁵⁸

The *National Policy for Persons with Disabilities 2021-2031* recognizes the need for increased access to GBV response systems for women with disabilities. In addition, reducing violence against women, persons with disabilities, and other groups is one of the policy outcome areas of the *National Policy on Family Safety: Elimination of Family Violence 2021-2031*.⁵⁹ However, none of these policies include an explicit outcome initiative or strategic action addressing GBV towards persons with disabilities.⁶⁰

“ Yes [I believe I was targeted because of my disability]. They say I am deaf. They say if they violate me (sex me) I don't go tell anyone. They think we are stupid.”
– Deaf woman, age 23.⁶¹

GBV services in Samoa are primarily provided through public justice and policing services, healthcare providers, and Samoa Victim Support Group (SVSG). NOLA refers survivors with disabilities to SVSG and provides support to those whose cases progress through the court system.⁶² Ramps, elevators, and rails are available at the Court House.⁶³ While all GBV services in Samoa are available to persons with disabilities, the lack of investment in disability-inclusive services through consistent training of providers, investment in information/communication accessibility mechanisms, and targeted empowerment programmes for persons with disabilities has rendered many of the services unavailable to people with disabilities in practice.⁶⁴

3.5. COVID-19

COVID-19 restrictions globally have substantially affected women and young people with disabilities in many ways, including through an increased risk of GBV, restrictions on education, and challenges to meeting basic needs.⁶⁵ According to the stakeholders and the people with disabilities interviewed, these global effects have been felt locally throughout Samoa.

Across the focus groups and individual interviews, women and young persons with disabilities reported experiencing difficulty getting enough food and money due to the COVID-19 restrictions.⁶⁶ Although none of the focus group and individual interview participants reported feeling unsafe in their homes during the COVID-19 lockdowns, many felt, along with the stakeholders interviewed, that the COVID-19 restrictions had led to an increase in violence towards people with disabilities.⁶⁷ For the young women with disabilities who were still in school, many experienced a disruption with their education due to the COVID-19 restrictions.⁶⁸

“ Just short of food, noodles, water, no money because of shortage of money. No money in the bank to do shopping because of covid problems everywhere.”
– Deaf woman, age 23, Vaitele-Uta.⁶⁹

Radio and TV programming were cited by the women and young people interviewed as their primary source for COVID-19 information.⁷⁰ Many women and young people with disabilities also reported that their family members were key in interpreting or explaining the restrictions further due to the lack of accessible information available to them to access independently.⁷¹ For Deaf women and men, access to TV programming with interpretation was an essential way for them to understand the COVID-19 restrictions and the pandemic.⁷² In their interviews, many of the Deaf women and men expressed the need for more information in captioned and sign language formats to be better able to understand the ongoing pandemic.⁷³ At least one woman with an intellectual disability experienced challenges in understanding the COVID-19 information available, even where pictures were used.⁷⁴

4 General recommendations

Summary of recommendations: Realization of Samoa’s commitment to respect, protect, and fulfill the rights of women and young people with disabilities to sexual and reproductive health and to be free from violence requires the development, investment, implementation, and monitoring of a robust twin-track approach to both SRH and GBV service provision by public, private, and non-governmental providers. The twin-track approach is the systematic mainstreaming of “the interests and rights of [people] with disabilities across all national action plans, strategies and policies concerning women, childhood and disability, as well as in sectoral plans concerning, for example, gender equality, health, violence, education, political participation, employment, access to justice and social protection” and “targeted and monitored action aimed specifically at women [and young people] with disabilities.”⁷⁵ Successful implementation of the following recommendations requires clear recognition and agreement on the role of—and adequate financial investment in— Samoan OPDs, including NOLA and its members—to ensure that they can meet the extensive demand for their expertise in a sustainable and equitable way.

Recommendation 1: Pass comprehensive legislation harmonizing Samoan law with the CRPD per *National Policy for Persons with Disabilities 2021-2031* Outcome 6. Ensure particular attention is paid to alignment with CRPD Articles 6 (women), 12 (equality before the law), 16 (freedom from violence), and 25 (health).

Recommendation 2: Engage and monitor the *National Policy for Persons with Disabilities 2021-2031* implementation:

- Seek UNFPA’s technical support, particularly relating to Indicator 18.⁷⁶
- Monitor implementation of the twin-track approach for each outcome to avoid overreliance on OPDs to implement the policy outcomes, as such an approach will hinder effectiveness and sustainability.
- Ensure that Indicator 13 includes all disabilities.

- Ensure that Indicator 30 includes SRH and GBV facilities.
- Monitor inclusion of CRPD Articles 6 (women), 12 (equality before the law), 16 (freedom from violence), and 25 (health) in Indicators 36 and 37.

Recommendation 3: Submit Samoa’s State Party report to the Committee on the Rights of Persons with Disabilities (originally due on 02 January 2019). Engage women and young people with disabilities in the reporting process and develop a plan to work together to implement the Committee’s Concluding Observations.

Recommendation 4: Invest adequate resources to ensure that SRH and GBV services—whether provided by public, private, or non-governmental entities—are accessible to people with diverse disabilities. Ensure that OPDs have sufficient support to strengthen and expand their SRH and GBV trainings for both public or non-governmental entities and people with disabilities, especially those from underserved disability communities and rural areas.

Recommendation 5: Integrate into the development, investment, implementation, and monitoring of SRH and GBV programming the requirement that public, private, or non-governmental SRH and GBV providers ensure that their mainstream services are accessible and that their staff are trained on disability-inclusion.

Recommendation 6: Ensure that people with disabilities are included in and considered in the development of any humanitarian emergency planning development, implementation and monitoring. Implement the *Inter-Agency Standing Committee Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action*.⁷⁷ Support the expansion of the Samoa Red Cross Society’s Peer Education programme to increase the number of peer educators trained on disability-inclusion and the number of peer educators with disabilities.⁷⁸

5

Legal and policy barriers

5.1. Issue 1: Informal deprivations of legal capacity are commonplace in Samoa.

Women and 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. Common ways this occurs in Samoa are through:

- Harmful stereotyping by both service providers and family members that a person with a disability cannot make a decision independently;⁷⁹
- Services that rely on third parties (often family members or OPDs) to provide interpretation or other accessibility measures, which restricts the ability of the person with the disability to make decisions independently;⁸⁰
- 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;⁸¹
- Disempowerment of persons with disabilities, which prevents people from understanding and advocating for their right to make an independent decision;⁸² 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.⁸³

The majority of focus group and interview respondents reported that family members made their decisions on their behalf regardless of their age.⁸⁴ In the healthcare context in particular, family members often accompany women and young people with disabilities to appointments and communicate directly with providers, including providing consent for medications or procedures on their behalf.⁸⁵ Women with disabilities report that healthcare provider's respect for their ability to make independent decisions for themselves ranges across service providers with some providers taking the time to enable a woman to make a decision for herself while others refuse to allow a woman with a disability to make her own decision and only speak directly to their family members.⁸⁶

Women with a variety of disabilities reported experiencing deprivations of their legal capacity when seeking SRH services, such as maternal healthcare.⁸⁷ One young woman with a physical disability reported that when she was in labor she refused to provide her consent for an epidural, but the doctors proceeded with the injection over her objections.⁸⁸ Ultimately the woman lost her baby during labor and has been left fearful of having another child. Another woman, who is a little person, reported that her doctors pressured her to abort her baby for her safety and that she had to fight hard to have her wishes respected to keep the baby.⁸⁹ While at least one other woman experienced being pressured to have an abortion by her family, explaining that: "Mum didn't want to have the baby. Doctor was there. Mum didn't want the baby. Grandfather didn't want. [I] have an injection to abort the baby...Family wanted me to terminate [the] pregnancy. [I feel] anger. Anger towards me. Angry towards me. Yes, I wanted to keep [the] baby... I was tired of their anger, so I agreed."⁹⁰

Numerous women described violations of their right to legal capacity by family members, particularly as it relates to the right to parenthood.⁹¹ At least three women had experienced forced adoptions directly following their pregnancies.⁹² Consistent across their experiences were family members who pressured or consented to the adoption against the will of the woman with the disability.⁹³ This failure to respect autonomous decision-making traumatized many of the women who wanted to be parents.⁹⁴

“ When I was pregnant, I was so looking forward to taking care of my baby because I was experienced in taking care of my other cousins and siblings. However, I didn’t know my parents had pre-arranged for a cousin of mine to take my baby and care for her. My family told me I cannot look after my baby. I felt so sad.”

– Deaf woman, age 23.⁹⁵

Multiple women and young men with disabilities reported that family members restricted their access to romantic partners, their freedom to leave the house, and, their ability to have or raise their own children.⁹⁶ For example, one young Deaf person explained that their family members restricted their movements and that their parent was violent towards them because they identify as fa’afafine⁹⁷ (traditionally recognized Samoan third gender).⁹⁸ Another woman with a physical disability described how her mother makes decisions for her and attends her health appointments, which makes her nervous to ask questions to the doctor.⁹⁹ This woman further explained that she has been in a relationship for eighteen years that she has hidden from her family out of fear that they would not approve of her being in a romantic relationship.¹⁰⁰ For many family members, these restrictions are driven by fear of the violence that people with disabilities experience in the community along with a lack of awareness of the rights of people with disabilities, especially relating to legal capacity.¹⁰¹

Deaf and hearing-impaired people and people with psychosocial and with intellectual disabilities are most at risk of deprivations of their legal capacity in

Samoa.¹⁰² Deaf and hearing-impaired women reported being unable to make their own decisions, with family members—most often their mothers—instead making decisions on their behalf no matter their age.¹⁰³ Lack of sign language interpretation in Samoan healthcare facilities is a major factor in why Deaf and hearing-impaired people with disabilities experience substitute-decision making. In general, Deaf and hearing-impaired women reported that doctors do not take the time to explain procedures, medication, or information to them and instead rely on family members to translate the information and provide consent.¹⁰⁴ Deaf and hearing-impaired women who had given birth in a hospital reported that no interpreters were available and throughout their pregnancies they were forced to rely on family members to communicate with the doctors who often refused to speak directly to the pregnant woman herself.¹⁰⁵

Due to this dependence on family members, people with disabilities are also restricted in their access to critical services. For example, one young Deaf woman who had been raped requested medical care but was denied by her mother.¹⁰⁶ Despite experiencing pain and wanting medical care, the young woman was unable to get the care because she was dependent on her mother to accompany her and communicate with the doctor.¹⁰⁷

As a result of this dependence, which is compounded by high rates of poverty and low employment rates among women with disabilities, many of them lack enough financial resources to cover the associated costs of healthcare. For example, one young Deaf woman described how when she is sick, she sometimes cannot see a doctor because her mom says there is no money.¹⁰⁸

Thus, while SRH services are currently free in Samoa, the associated costs (i.e. the costs of accessible transportation for the individual and their support person, sign language interpretation, Braille materials, etc.) can be prohibitively expensive for people with disabilities who are economically dependent on their families.¹⁰⁹ Given the lack of appropriate State mechanisms in place to guarantee the availability of these accessibility measures and/or cover their costs, many people with disabilities have to request the support of local OPDs, which already face high demands for these accessibility services.

5.2. Issue 2: Access to justice is limited for people with disabilities in Samoa, particularly for women and young people experiencing GBV.

In Samoa, women and young people with disabilities often face insurmountable barriers to accessing justice for the GBV that they experience. Barriers include inaccessible justice system information and reporting systems; stakeholders without training on disability-inclusion, and disempowerment of people with disabilities. However, there is substantial opportunity to address these barriers in Samoa as there is a recognized commitment to addressing violations against people with disabilities.¹¹⁰

Currently, the Samoan police lack the comprehensive procedures to handle and investigate reports of violence involving people with disabilities and do not have accessibility mechanisms available to enable people with disabilities to report violence independently.¹¹¹ For women and young people with disabilities who seek to report violence to the police, many experience attitudinal barriers from both police officers (who are unwilling to accept their statements) and from family members (who discourage them from reporting GBV incidents to the police).¹¹² Stakeholders report that the Samoan police are open to increasing their capacity to serve Samoans with disabilities, but lack of resources currently hinders systemic change from taking place.¹¹³

“ [Following my rape], my cousin took me to [the] police. She was unfamiliar with [the] procedures. My cousin didn’t understand my signs [and the] police didn’t quite understand. We went to police station in Savaii, the police didn’t file our case. We couldn’t find the records. The police got sacked.”

–Deaf woman, age 23.¹¹⁴

Whether because of inaccessible systems, lack of awareness, or attitudinal barriers, most women and young people reported that they did not or would not use the formal justice system to seek redress for GBV.¹¹⁵ For those that had experienced GBV, the violence had primarily been addressed through family interventions rather than seeking justice through formal mechanisms.¹¹⁶ Those interviewees who had reported violence to the police required the assistance of a family member to make the process accessible especially if they required an interpreter to communicate.¹¹⁷ However, for those who successfully reported violence to the police or had heard of such case, perpetrators were reported to be convicted.¹¹⁸ When asked how they would report future GBV experiences should they occur, most women and young people with disabilities stated they would report such violence to a church representative or the village council rather than the police.¹¹⁹

One of the consequences of the lack of accountability for perpetrators of GBV against people with disabilities in Samoa is that it can lead to further rights violations. Fears over high rates of GBV committed against women with disabilities can lead family members to restrict their rights. Multiple women with disabilities reported that their family members restricted their movements, including by removing their mobility devices, to protect the woman from the perceived risk of violence she faced in the community.¹²⁰

5.3. Issue 3: Referral pathways between SRH, GBV, and disability-service providers require strengthening.

Robust referral pathways between SRH, GBV, and disability-service providers are particularly essential for women and young people with disabilities because of the heightened barriers that people with disabilities face in accessing services.¹²¹ Where referral pathways between providers are deficient, these barriers can become insurmountable for people with disabilities given the added accessibility barriers and discrimination they experience. In Samoa, referral pathways between the health sector and victim support services require strengthening, especially for people with disabilities.¹²² Currently, one of the strongest referral pathways in place is between NOLA and SFHA due to the Memorandum of Understanding between the two organizations.¹²³

Counseling services in Samoa in general require improvement, including with respect to counselors trained to also serve as case coordinators identifying SRH and GBV issues and referring clients to essential services accordingly.¹²⁴ Only three of the twenty-one women and young people interviewed reported being referred to or seeing a counselor for psychosocial support.¹²⁵ Generally, the counselors available in Samoa are not trained to support victims/survivors with disabilities (particularly those with developmental disabilities).¹²⁶

Recommendations to address legal and policy barriers

Recommendation: Pass legislation enumerating the right of people with disabilities in Samoa to legal capacity consistent with Article 12 of the CRPD. Develop policies and monitoring mechanisms to address common forms of informal deprivations of legal capacity, particularly in SRH settings. Create awareness raising programmes for people with disabilities and for their families relating to legal capacity.

Recommendation: Invest in system-wide disability-inclusion capacity building for public and non-governmental providers in the healthcare and the justice sectors. For the justice sector, include both the formal and customary systems. Support OPD engagement in such capacity-building programmes.

Recommendation: Prioritize increasing accessibility in the healthcare and the justice sectors through improving and developing access to sign language interpretation and other accessible formats. For example, partner with the Deaf Association of Samoa to train healthcare workers and justice system staff on sign language and to coordinate interpretation services. Plan for long-term investment in increasing the number of sign-language interpreters available in Samoa and the hiring of permanent sign language interpreters within the healthcare and the justice sectors.

Recommendation: Establish and fund effective referral pathways between key SRH, GBV, and disability-service providers in Samoa. Further enumeration of the referral pathways and roles and responsibilities between non-governmental providers, public providers, OPDs, and government ministries - along with funding for these referral pathways - are required to ensure sustainability and improve effectiveness. Develop and support training programmes for SRH and GBV counselors on how to support people disabilities and implement effective case coordination through effective referrals pathways.

6 Social and attitudinal barriers

6.1. Issue 1: Women and young persons with disabilities in Samoa experience ongoing stigma and discrimination.

Attitudinal barriers are one of the primary obstacles to full disability-inclusion in Samoa.¹²⁷ In the SRH and GBV contexts, these barriers manifest in the form of family members who do not recognize their family member with a disability's rights; healthcare practitioners who refuse to speak directly to the person with the disability; and perpetrators who target people with disabilities because they are viewed as more vulnerable and less valuable.¹²⁸ In Samoa, these attitudinal barriers are driven by a general lack of comprehensive understanding of the equal rights of people with disabilities by both the average Samoan and service providers.¹²⁹ For example, while there is increasing recognition of the rights of people with disabilities under the CRPD, there is limited understanding and support for capacity building regarding specific rights such as accessible SRH services under Article 25.¹³⁰ Another example, is that mental health related disabilities are particularly stigmatized and have not been prioritized as part of the CRPD implementation and programming in Samoa thereby further deepening the stigma experienced by people with psychosocial disabilities.¹³¹

Consistently across interviews with women and young men with disabilities, each person reported experiencing being teased as a child because of their disability.¹³² Many also reported that such attitudes continued into adulthood, alongside other forms of discrimination such as exclusion, isolation, and violence.¹³³ These forms of discrimination extend into the SRH service-provision realm, with multiple interviewees reporting experiencing being teased or feeling discriminated against by nurses as part of their SRH care.¹³⁴ For those women with disabilities who had received a health check-up at SFHA, the experience had generally been a good one, with respondents reporting that the facilities

were accessible and welcoming.¹³⁵ However, public hospitals and doctors were reported to be much less hospitable and women faced greater attitudinal barriers when accessing SRH services at these facilities.¹³⁶

“ When I went to have a baby, some doctors and nurses were very good. But some, they don't say but their body language, it's like I've committed a sin.” - Woman with a physical disability, age 32.¹³⁷

In Samoa, women with disabilities face particular stigma from community members, family members, and healthcare providers relating to having children.¹³⁸ This attitudinal barrier seems to be primarily driven by stereotypes that a woman with a disability will give birth to a child with a disability and assumptions that the woman will be unable to care for the child.¹³⁹ For women with disabilities already raising children, some reported feeling supported by their village community, while others felt isolated and discriminated against by their community, teachers, and medical providers.¹⁴⁰ Amongst the young men with disabilities interviewed, many wished to also become parents but expressed concern at the lack of support available to and stigma experienced by parents with disabilities.¹⁴¹

Furthermore, women and young people with disabilities experience discrimination in the provision of GBV services as well. While SVSG's Caregiving Programme for Persons with Disabilities is an essential programme to address family violence against children with disabilities and provide support for families, it can also contribute to the institutionalization of children with disabilities.¹⁴²

Anecdotal reports indicate that some young persons with disabilities who sought GBV services experienced pressure to be adopted by international parents, rather

than addressing the abuse experienced within their Samoan families.

6.2. Issue 2: Women and young people with intellectual disabilities in Samoa face unique forms of discrimination.

Under-diagnosis of disabilities and inadequate early intervention systems are a recognized systemic problem in Samoa.¹⁴³ As a result, the number of Samoans with intellectual disabilities is currently unclear – census data is not disaggregated by form of cognitive disability and no targeted studies have been conducted. Due to the limited diagnostic services in the country many people and their families have not received an accurate diagnosis.¹⁴⁴ A recent survey by NOLA estimated that the number of community members with intellectual disabilities is much higher than previously realized and that often there are multiple family members with intellectual disabilities.¹⁴⁵

The attitudinal barriers and stigma experienced by Samoans with intellectual disabilities is often greater than for people with other disabilities.¹⁴⁶ Samoans with intellectual disabilities face increased isolation, a lack of support services for them as individuals and for their families, and limited educational services.¹⁴⁷ These barriers further impede their access to empowering opportunities, including engaging with NOLA. For example, NOLA has tried to organize a self-advocacy group for members with intellectual disabilities but for the foregoing reasons has not yet been successful. Moreover, NOLA currently requires more capacity to be able to fully support and assess the needs of community members with intellectual disabilities.¹⁴⁸ Lack of access to education and empowerment services means that Samoans with intellectual disabilities are often excluded from the SRH and GBV programming that is available through NOLA and school settings.

While on their face health services, including SRH services, are available to persons with intellectual disabilities, in reality few measures have been taken to make services independently accessible for this population.¹⁴⁹ For example, there are no widely available easy-read¹⁵⁰ or simplified format SRH materials or sexuality education programmes tailored for persons with intellectual disabilities. The four people with intellectual disabilities interviewed had received very little SRH information and expressed discomfort or an inability to discuss SRH-related topics.¹⁵¹ Another woman explained during her focus group that she knew of a woman with an intellectual disability whose mother had sought to have her sterilized.¹⁵²

Service providers typically are not trained to offer services to people with cognitive disabilities like intellectual disabilities.¹⁵³ Current practice is to seek consent directly from the person's parent and never speak to the person alone.¹⁵⁴ Consequently, people with intellectual disabilities are especially at risk of violations of their right to legal capacity.

Recommendations to address social and attitudinal barriers

Recommendation: Develop disability-specific values clarification trainings – particularly for healthcare providers, including doctors and nurses - aimed at dismantling harmful stereotypes about people with disabilities and providing training on soliciting informed consent from people with a variety of disabilities.

Recommendation: Create and expand rights-based awareness-raising programmes on disability rights and inclusion, with a particular focus on ensuring that such programmes are made available and accessible to the following audiences:

- Women with disabilities.
- Young people with disabilities.
- Deaf and hearing-impaired people.
- People with intellectual disabilities.
- Family members of people with disabilities, particularly parents.
- Healthcare providers, especially SRH doctors and nurses.
- GBV service providers, including members of the formal and informal justice sector.
- Community members, particularly women's committees and religious leaders.

Programing must be grounded in the CRPD framework and developed in consultation with OPDs and led by people with disabilities whenever possible. Key topics to be addressed include: SRH and GBV rights and services for people with disabilities; legal capacity, including informed consent in healthcare settings; and family violence.

Recommendation: Address the under-diagnosis of intellectual disabilities in Samoa and invest in the development of an early intervention and support-services system for people with intellectual disabilities and their families. Support the development of empowerment and self-advocacy programmes aimed at people with intellectual disabilities, particularly those that prioritize training and empowerment on SRH, GBV, and informed decision-making. For example, create family life education programming for students with intellectual disabilities and their teachers.

7 Physical barriers

7.1. Issue 1: Physical accessibility in Samoa, particularly telecommunication accessibility, requires ongoing investment and improvement.

SRH and GBV services in Samoa have good basic physical accessibility for people with disabilities, primarily for those who use wheelchairs.¹⁵⁵ However, as Samoa continues to develop its infrastructure, particularly as part of cyclone rebuilding efforts and development, improving physical accessibility for all people with disabilities to enable independent access to services is essential.¹⁵⁶ For example, the Ombudsman has documented issues with the quality of some of the ramps that are available and the inaccessibility of footpaths and roads which impede independent access to services.¹⁵⁷ Moreover, there are no physical accessibility standards for public transportation in Samoa, which creates a substantial barrier to people with disabilities in accessing SRH and GBV services independently.¹⁵⁸

The *National Policy for Persons with Disabilities 2021-2031* includes Strategic Outcome 5 on strengthening access to the built environment, information and communication, transport and other services and facilities.¹⁵⁹ SRH or GBV services are not explicitly considered but are within the scope of the initiatives and activities in the Policy. Under Priority Area 6 of the *National Policy on Gender Equality & Rights of Women & Girls 2021-2031*, the State aims to ensure that all transport and infrastructure planning incorporates gender analysis, including with respects to the interests, needs and experiences of women and people living with disabilities.¹⁶⁰

Telecommunication access for people with disabilities, especially for SRH and GBV services, is a key area for improvement in Samoa. There are no disability-related accessibility requirements for telecommunication in Samoa.¹⁶¹ The Ministry of Communications and Information Technology, however, appears to recognize the steps necessary to make telecommunication accessible, having recently posted on their website the UN's International Telecommunication Union Guidelines on making COVID-19 information accessible to people with disabilities.¹⁶²

Due in part to the lack of accessible telecommunication options available, SRH and GBV services are primarily only accessible to people with disabilities through in-person visits to the SFHA and SVSG offices.¹⁶³ None of the public health facilities, SFHA, or SVSG have the capacity yet for accessible talk-to-text hotlines or other accessible mechanisms for soliciting services independently. For example, SFHA relies on NOLA to help identify people with disabilities who require outreach as part of mobile clinic outreach visits.¹⁶⁴ NOLA also helps facilitate appointments for people with disabilities at both SFHA and SVSG, particularly for people who cannot call the clinic phone number to make an appointment themselves.¹⁶⁵ Both are good practices that should be expanded but also paired with options for people with disabilities to communicate directly and independently with service providers.

Recommendations to address physical barriers

Recommendation: Incorporate accessibility for SRH and GBV services into all relevant initiatives and activities in Strategic Outcome 5 of the *National Policy for Persons with Disabilities*. Conduct an accessibility audit with people with diverse disabilities of policies, plans, and facilities (including, for example, the Samoa National Action Plan for Disaster Risk Management and any future National Information and Communication Technology policies) to identify specific areas for strengthening.

Recommendation: Develop a strategic plan relating to disability-accessible telecommunication addressing barriers to accessing SRH and GBV services. The Ministry of Communications and Information Technology should provide accessibility-specific funding for public and non-governmental SRH and GBV service providers, including for accessible telecommunication services (e.g. phone lines, information materials).

8

Information and communication barriers

8.1. Issue 1: SRH and GBV awareness-raising information is often inaccessible in Samoa.

Lack of accessible awareness-raising materials present one of the biggest barriers for women and young people with disabilities to understanding their sexual and reproductive health and rights and their right to be free from gender-based violence along with the related services available to them. Both SFHA and SVSG recognize that their awareness-raising materials are not fully accessible and cite this as one of their primary areas for improvement when funding allows.¹⁶⁶ For example, SFHA's bi-weekly Good Morning Samoa TV awareness raising spot, does not currently feature sign-language interpretation or captioning.¹⁶⁷ Similar issues are recognized by SVSG, whose information campaigns are primarily in the form of brochures, media releases, road signs and social media, which are not accessible to people with visual impairments, some hearing-related impairments, or intellectual disabilities.¹⁶⁸ For example, one young Deaf man attended SVSG's village programme on GBV but was unable to understand the information presented unless his parents explained it to him.¹⁶⁹ Awareness-raising materials and programming from the Ministry of Health and Ministry of Women, Community and Social Development appear to have similar accessibility issues.

SRH awareness raising and information

Samoa women and young people with disabilities are equally sexually active as their peers without disabilities and yet are often unable to access the awareness-raising programming and information

available to the rest of the population. Across focus group discussions and individual interviews, women and young people with disabilities report discomfort in accessing and discussing SRH services;¹⁷⁰ limited access to accessible SRH information, including awareness-raising material on sexually transmitted infections (STIs) or family planning methods; and discomfort using family planning methods.¹⁷¹ Many of the women and young people with disabilities interviewed had not received any SRH information despite their interest or experience in having sexual partners and accessing SRH services.¹⁷² Most women and young people with disabilities who had learned about their SRH had done so through information provided by NOLA,¹⁷³ other sources included school settings; SFHA, and family members.¹⁷⁴

Deaf and hearing-impaired women in particular noted that they were unable to receive SRH and family planning information because of the lack of sign-language accessible SRH programming and exclusion from mainstream school settings.¹⁷⁵ For example, one 47 year-old Deaf woman from a rural area reported only learning about how a woman gets pregnant and how to use a condom when she began working at SENESE (a specialized school and organization for Deaf people) —over 20 years after giving birth to her children.¹⁷⁶ A young hearing-impaired man who attended a mainstream school without interpretation reported never learning about family planning methods or receiving any SRH information, despite being sexually active.¹⁷⁷ Most Deaf and hearing-impaired people interviewed reported learning about SRH from a volunteer-led programme at SENESE.¹⁷⁸

Most people interviewed reported never receiving a female or male health-check-up. In general, women with disabilities only sought SRH services when they became pregnant. For those that had received a health-checkup, only one¹⁷⁹ out of fifteen female interviewees had received a breast exam or a cervical cancer exam.¹⁸⁰ Similarly, most of the young men with disabilities who were interviewed had never sought healthcare services for their SRH (besides receiving circumcisions in their early teenage years).¹⁸¹

Of the women and young people interviewed, 14 of the 21 had received information about STIs and how to protect themselves.¹⁸² Five of the twenty-one people had received an STI test.¹⁸³ For at least two young men with disabilities, the results of the test had not been shared with them.¹⁸⁴ Limiting sex to one partner and using a condom were the two most commonly cited ways to protect oneself from STIs.¹⁸⁵ Those people who had learned about STIs still feared getting tested. For example, one Deaf person who identifies as fa'afafine (third gender) expressed that they have had sex with multiple married men and fear having an STI test as a result.¹⁸⁶

Across the focus groups and interviews, most women and young people had never sought family planning services. Condoms were the preferred method of choice for those who had learned about family planning methods.¹⁸⁷ However, the majority of interviewees—including those who had learned about family planning—remained uncomfortable with utilizing and seeking out family planning methods, often resulting in an unplanned pregnancy.¹⁸⁸ Unmarried women, in particular, reported experiencing shame at accessing or using family planning methods.¹⁸⁹

“ I am not sure about parts of the body. I do not know that sort of information... I don't know anything about sexual or body parts. I see neighbor girls having babies, I don't know how it happened.”
– Deaf woman, age 23.¹⁹⁰

GBV awareness raising and information

Despite the high rates of GBV in Samoa, women and young people with disabilities generally lack access to accessible information on GBV and related

services. Throughout the focus group discussions and individual interviews, numerous women and young people reported experiencing GBV.¹⁹¹ People with a range of disabilities and backgrounds described experiencing physical, sexual, economic, and emotional violence and abuse.¹⁹² Family members were identified as the most common perpetrator, followed by community members.¹⁹³ Of the six young men with disabilities interviewed, three had been raped at least once as a child.¹⁹⁴ Multiple young women and men with disabilities had experienced violence in school.¹⁹⁵ Women and young men with disabilities from a variety of backgrounds reported experiencing regular physical violence at home, generally as a consequence of disobeying a direction from their parent or from a sibling.¹⁹⁶

Deaf and hearing-impaired women and young people in particular reported the highest rate of GBV of those interviewed, with many reporting being raped at a very young age; these interviewees believe they were targeted because of their disability.¹⁹⁷ Survivors reported being raped as young as seven and eight years-old.¹⁹⁸ One person reported that they were repeatedly sexually assaulted by family members for two-years despite informing their family about the abuse.¹⁹⁹ The abuse only stopped when they left their family home.²⁰⁰

Nevertheless, the majority of people interviewed had not received information about GBV and did not feel empowered to address such violence.²⁰¹ For the few women and young people with disabilities interviewed who had received information on GBV and healthy relationships, this information came primarily from NOLA and TV spots.²⁰² When asked about areas requiring further awareness-raising, women and young people with disabilities identified healthy relationships and the availability of GBV services as two key areas.²⁰³

“ It's difficult for me to find a loving person because of my disability and of what happened [when I was raped]. That's why I like free sex. I go with them and no strings attached.”
– Deaf person, age 23.²⁰⁴

8.2. Issue 2: Information, education and communication materials at health facilities are generally inaccessible in Samoa.

Health services in Samoa typically do not enable a person with a disability to independently access services. For example, information is generally not available in sign language, braille, or simplified formats like easy-read.²⁰⁵ As a result, most women and young people with disabilities must rely on NOLA or a family member to accompany them to access SRH services. This potentially prohibitive barrier to accessing services can also contribute to a range of rights violations, including violations of a person's right to privacy, informed consent, and the right to accessibility on equal basis with others.²⁰⁶

Public and SFHA SRH services currently rely on NOLA to provide training and support services to make information, education and communication (IEC) materials accessible at health facilities. SFHA is committed to providing services for people with disabilities and has a robust training programme for staff supported by NOLA and Family Planning New South Wales.²⁰⁷ Generally, in both the public and non-governmental sector, the reliance on NOLA to provide trainings, awareness-raising, and sign language interpretation services to ensure that IEC materials are accessible is unsustainable. NOLA already faces high demands on its members' time, and, at present, there does not seem to be sufficient allocation of resources to sustain this demand or permit a scaling up of such efforts.²⁰⁸

The current lack of accessible IEC materials at healthcare clinics prevents people with disabilities from being able to independently access information from healthcare providers and impedes the care received (e.g., during childbirth).²⁰⁹ One Deaf woman described how when she was pregnant, she would attend "trainings" with her sister but was unable to understand any of the information being conveyed. As a result, her sister participated in her place but did not share the information with the woman.²¹⁰ Interviewees with a range of disabilities reported that healthcare providers spoke directly to their support person rather than explaining the information to the person receiving the care.²¹¹ As a result of this dependence on a

third-party to be present, confidentiality of information is a concern for many women with disabilities when accessing these already sensitive services.²¹²

“ I cannot go to the doctor by myself or make decision. It's always mother who communicates to the doctor and the doctor talk to my mother”

– Woman with a visual impairment, age 54.²¹³

This is particularly so for Deaf people and people with hearing-impairments who require sign language interpretation.²¹⁴ Numerous Deaf and hearing-impaired women described how doctors generally do not take the time to explain procedures, medication, or information to them and instead rely on family members to translate the information and provide consent.²¹⁵ For example, one young Deaf woman described how doctors generally do not speak to her nor do they explain the medication they prescribe. As a result, she does not understand the medications she takes.²¹⁶ However, it should be noted that despite the lack of interpreters, some women did encounter doctors who made the effort to communicate directly with them.²¹⁷

The inaccessibility of health services in Samoa also impacts women and young people with disabilities seeking healthcare services in response to GBV. For most of the women and young people interviewed, they did not seek out health services after experiencing violence.²¹⁸ Those who did seek out healthcare services after experiencing GBV reported encountering inaccessible services and pressure to proceed with a pregnancy resulting from rape.²¹⁹ Of the nine sexual GBV survivors interviewed who sought healthcare services after being raped, only one of the survivors was offered psychosocial services.²²⁰ SVSG's programming, while welcoming of people with disabilities, does not offer accessible IEC materials or have disability-inclusive mechanisms in place to support people with disabilities in seeking healthcare services.²²¹

8.3. Issue 3: People with disabilities usually do not have access to family life education in Samoa.

Comprehensive sexuality education (CSE) is not broadly available in Samoa; however, a family life education (FLE) programme is currently under development by the Ministry of Education, Sports and Culture.²²² FLE is the term used in place of CSE throughout the Pacific. There are limited educational services for students with disabilities in Samoa.²²³ Mainstream and special education schools are available, however, teachers are reportedly often overwhelmed and lack the skills and capacity to support students with disabilities.²²⁴ For example, some parents report that their child with a disability is often left in the corner of the classroom and ignored by the teacher.²²⁵ There are also reports of violence against children in school.²²⁶ For example, one young man with a hearing-impairment explained that he was hit in school for not understanding his lessons because of the lack of interpretation.²²⁷ Given the challenges in both mainstream and specialized schools, where FLE is available in school many young people with disabilities cannot access it.

“ The reason I got expelled [was] because I fought. I didn’t understand, [and there was] no interpreter to interpret lessons. I got hit in school for not knowing how to do other subjects i.e. math.”

– Man with a hearing-impairment, age 20.²²⁸

For Deaf and hearing-impaired women and young people who attended SENESE or another specialized school where they could learn sign language, the experience was extremely empowering and had given them access to good educational services, including SRH information.²²⁹ SENESE’s SRH education class—developed and run by a volunteer—was cited multiple times by interviewees as a key source of SRH information (including family planning methods) for the Deaf and hearing-impaired community.²³⁰ One young man explained how important these sources of information are because families sometimes withhold information on SRH from people with disabilities.²³¹

Women and young persons with physical and visual disabilities primarily reported that they had not received any education about their sexual and reproductive health, despite attending school.²³² For those that had, many had received the information through NOLA outside of the school setting.²³³ The FLE available through NOLA was developed with support from SFHA.²³⁴ The programming available is small in scope but covers basic SRH information including STIs and family planning methods.²³⁵ However, for rural women, family members and visiting community nurses were their primary source of information.²³⁶ Women with intellectual disabilities were unable to answer the question as to where they had or could learn about FLE topics.²³⁷

Recommendations to address information and communication barriers

Recommendation: Develop - in association with NOLA, SFHA, and SVSG – accessible SRH and GBV IEC materials specifically targeting women and young people with disabilities to improve their awareness about their SRH, GBV, and the services available to them. Whenever possible invest in or create programmes to support persons with disabilities to deliver the IEC materials. Develop and disseminate accessible IEC materials for healthcare, particularly SRH services, and GBV services, including in braille, digital and/or audio formats, simplified formats such as easy-read, and in sign language.

Recommendation: Establish a community health-liason programme to address perceptions that SRH and GBV services are not for people with disabilities and to provide accurate and accessible information, particularly to rural areas. Health-liasons should be trained in tackling harmful stereotypes about people with disabilities held by the family members and the community and internalized by people with disabilities. Recruit people with disabilities to serve as health-liasons.

Recommendation: Expand the disability-inclusivity of the Ministry of Women, Community and Social Development's Nation Wide Gender-Based Violence Awareness Programme and the Village Family Safety Committees, to ensure such programmes meaningfully include people with diverse disabilities and that good practices are expanded country-wide.

Recommendation: Ensure broad consultation with a range of OPDs, disability service providers, and specialized schools in the development of Samoa's FLE programming to guarantee that course content and materials are accessible and tailored to people with diverse disabilities, including students with intellectual disabilities, psychosocial disabilities and who are deaf.

Endnotes

- 1 UNFPA, Danish Institute for Human Rights, & OHCHR, *Reproductive rights are human rights: a handbook for national human rights institutions*, at 18, U.N. Doc. HR/PUB/14/16 (2014), <http://www.ohchr.org/Documents/Publications/NHRI-Handbook.pdf>
- 2 *Id.* at 19.
- 3 Convention on the Rights of Persons with Disabilities, art. 25, G.A. Res. 61/106, U.N. Doc. A/RES/61/106 (Dec. 13, 2006) [hereinafter CRPD].
- 4 CRPD Committee, *General Comment No. 1 (2014) Article 12: Equality Recognition Before the Law*, para. 13, U.N. Doc. CRP-D/C/GC/1 (May 19, 2014) [hereinafter CRPD Committee, General Comment No. 1].
- 5 *Id.* at para. 12.
- 6 For good practices on seeking informed consent from people with disabilities in SRH settings, see United Nations Population Fund & Women Enabled International, *Women and young persons with disabilities: Guidelines for providing rights-based and gender-responsive services to address gender-based violence and sexual and reproductive health and rights* 16 – 19 (Nov. 2018), <https://www.unfpa.org/featured-publication/women-and-young-persons-disabilities> [hereinafter UNFPA & WEI, GBV and SRHR guidelines].
- 7 Women Enabled International, *Legal capacity of women and girls with disabilities 1*, <https://www.womenenabled.org/pdfs/Women%20Enabled%20International%20-%20Legal%20Capacity%20of%20Women%20and%20Girls%20with%20Disabilities%20-%20English.pdf?pdf=GBVEnglish> [hereinafter WEI, LEGAL CAPACITY FACTSHEET]
- 8 *Id.*
- 9 See CRPD Committee, *General Comment No. 1*, *supra* at note 4, at para. 52.
- 10 *Id.* at para. 29.
- 11 UNFPA & WEI, GBV AND SRHR guidelines, *supra* note 6, at 20-21.
- 12 Inter-Agency Standing Committee (IASC), *Guidelines for Integrating Gender-based Violence Interventions in Humanitarian Action: Reducing Risk, Promoting Resilience and Aiding Recovery* 322 (Aug. 2015), https://interagencystandingcommittee.org/system/files/2015-iasc-gender-based-violence-guidelines_lo-res.pdf
- 13 Women Enabled International, *The right of women and girls with disabilities to be free from gender-based violence*, <https://www.womenenabled.org/pdfs/Women%20Enabled%20International%20Facts%20-%20The%20Right%20of%20Women%20and%20Girls%20with%20Disabilities%20to%20be%20Free%20from%20Gender-Based%20Violence%20-%20ENGLISH%20-%20FINAL.pdf?pdf=GBVEnglish> [hereinafter WEI, GBV FACTSHEET]
- 14 United States Agency for International Development (usaid), *United States strategy to prevent and respond to gender-based violence globally* 7 (Aug. 10, 2012), <http://www.state.gov/documents/organization/196468.pdf>. It is worth noting that no global data exists on the incidence of such violence, and studies draw on different sources of data.
- 15 WEI, GBV factsheet, *supra* note 13.
- 16 Young people are defined for the purposes of this research as girls and boys ages 15 – 24. See UNFPA, *Girlhood, Not Motherhood: Preventing Adolescent Pregnancy* 6 (2015).
- 17 See UNFPA & WEI, GBV and SRHR guidelines, *supra* note 6.
- 18 Ministry of Women, Community and Social Development, *Pacific Island Forum Secretariat, Women: Matai and Leadership Survey* (2015).
- 19 See Office of the ombudsman & national human rights institution, *state of human rights report: persons with disabilities 19-20* (2016) [hereinafter ombudsman, persons with disabilities report]; Zoom Interview with Loukinikini Vili, Director of Human Rights, Office of the Ombudsman, Samoa National Human Rights Institution (Aug. 20, 2020).
- 20 Office of the Ombudsman Interview, *supra* note 19; Ombudsman, persons with disabilities report, *supra* note 19, at 40.
- 21 See e.g. Focus group interview by Faaolo Utumapu-Utailesolo with men with disabilities, in the NOLA Conference Room, Apia (Jan. 26, 2021); Focus group interview by Faaolo Utumapu-Utailesolo with women who are deaf, in the NOLA Conference Room, Apia (Dec. 17, 2020); Focus group interview by Faaolo Utumapu-Utailesolo with women who are blind/have physical disabilities, in DPO Office, Apia (Dec. 14, 2020).
- 22 Spotlight Initiative, *Country Programme Document Samoa* 10 (July 2019), <http://mptf.undp.org/factsheet/project/00119126> [hereinafter Spotlight Report]
- 23 Samoa Bureau of Statistics, *Prevalence of Disability in Samoa* (2019), https://www.sbs.gov.ws/images/sbs-documents/Population_and_Demography/Samoa%20Disability%20Monograph/Prevalence_of_Disability_Samoa_2018.pdf_final.pdf
- 24 WHO and World Bank Group (WBG), *World Report on Disability* 28 (2011), http://www.who.int/disabilities/world_report/2011/en/index.html (“Countries are divided between low-income and high-income according to their 2004 gross national income (GNI) per capita (36). The dividing point is a GNI of US\$ 3255. Source (37)”). According to the WHO data, lower income generally have a female with disabilities population percentage of 22.1 and 3.3 percent depending on the categorization of the data. *Id.*

- 25 Samoa Bureau of Statistics, Ministry of Women, Community and Social Development Pacific community and UNICEF Pacific, 2018 Samoa disability report: an analysis of 2016 census of population and housing 12 (2018) [hereinafter Disability Monograph]. The 2016 Census utilized the globally recommended Washington Group Short Set of Questions. However, in 2016 questions for the children had not yet been developed and were thus not included leading to a gap in data on this subpopulation. *Id.* at 7.
- 26 *Id.* at 12.
- 27 *Id.* at 8.
- 28 *Id.*
- 29 As of this writing, the Samoan Government has not yet submitted their State party report that was due in January 2019.
- 30 Office of the High Commissioner on Human Rights, *Human Rights by Country: Samoa* (last accessed March 21, 2021), <https://www.ohchr.org/EN/Countries/AsiaRegion/Pages/WSIndex.aspx>
- 31 Incheon Strategy to “Make the Right Real” for Persons with Disabilities in Asia and the Pacific (2012), <https://www.unescap.org/resources/incheon-strategy-%E2%80%9Cmake-right-real%E2%80%9D-persons-disabilities-asia-and-pacific>; Biwako Plus Five: Further Efforts towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific, U.N. Doc. E/ESCAP/APDDP(2)/2* (Nov. 13, 2007); Biwako Millennium Framework for Action Towards an Inclusive Barrier-Free and Rights-Based Society for Persons with Disabilities in Asia and the Pacific, U.N. Doc. E/ESCAP/APDDP/4/Rev.1 (Jan. 24, 2003).
- 32 Ministry of Women, Community and Social Development, National Policy for Persons with Disabilities 2021-2031 3 (July 2021), <https://www.mwscsd.gov.ws/index.php/publications-all> [hereinafter National Policy for Persons with Disabilities].
- 33 *Id.* at 12-13.
- 34 *Id.* at 14-15.
- 35 National Policy for Persons with Disabilities, *supra* note 32, at 18.
- 36 Zoom Interview with Mataafa Faatino Utumapu, Manager, Nuanua O Le Alofa (NOLA) (July 23, 2020).
- 37 UNFPA Pacific Sub-Regional Office, Samoa: Sexual and reproductive health rights needs assessment 7 (April 2015), <https://pacific.unfpa.org/sites/default/files/pub-pdf/2.SamoaSexualandReproductiveHealthRightsNeedsAssessmentReportLRv1.pdf>
- 38 SUNGO, *NGO CEDAW Shadow Report for Samoa* 3 (2018) [hereinafter SUNGO Report] (“In 2017, Samoa declared itself to be a Christian nation by Constitutional Amendment. Over 90% of the population attend Church regularly); Zoom Interview with Dr. Ibironke Oyatoye, Sexual and Reproductive Health Specialist, UNFPA Samoa (June 11, 2020).
- 39 National Policy for Persons with Disabilities, *supra* note 32, at 10.
- 40 Ministry of Women, Community and Social Development, National Policy on Gender Equality & Rights of Women & Girls 2021-2031 12 (July 2021) [hereinafter National Policy on Gender Equality] In addition, strengthened health services for persons with Disability and “sexual reproductive health rights for vulnerable groups” are some of the outcomes of the *Strategic Corporate Plan* of the Ministry of Women, Community and Social Development 2021-2026. Ministry of Women, Community and Social Development, *Strategic Corporate Plan* 31 (2021)
- 41 SUNGO Report, *supra* note 38, at 19.
- 42 Samoa Bureau of Statistics, *Reproductive Health & Disability Status for Women* (2019), https://www.sbs.gov.ws/images/sbs-documents/Population_and_Demography/Samoa%20Disability%20Monograph/Reproductive_Health_Samoa_2018.pdf_final.pdf. Specifically, 20% of women with disabilities had their first birth between age 15 to 18 years old as compared to 12% of women without disabilities.
- 43 *Id.* (Women with disabilities on average have 1.6 children while women without disabilities have an average of 2 children).
- 44 Disability Monograph, *supra* note 25, at 31-33 (4 out of 10 women with disabilities are no longer married as compared to 1 out of 10 women without a disability).
- 45 *Id.* at 31 (52% of men with disabilities surveyed were married as compared with 28% of women with disabilities).
- 46 See e.g. Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview by Faaolo Utumapu-Utailesol with rural women with disabilities, in Jet Over Hotel, Salelologa (2020); Focus group interview with women who are deaf, *supra* note 21; Focus group interview with men with disabilities, *supra* note 21.
- 47 *Id.*
- 48 *Id.*; NOLA Interview, *supra* note 36.
- 49 Mental Health Act 2007, Part II, Sections. 5-6. The Mental Health Act includes a provision enumerating a preference for “voluntary care, support and treatment” by a person’s family and the community where they live (Pertaining to persons with psychosocial disabilities. People with intellectual disabilities are specifically excluded from the definition of a person with a mental disorder under the Act).
- 50 Evidence Act 2015 (art. 9(2)(c)).
- 51 See NOLA Interview, *supra* note 36; Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Interview by Faaolo Utumapu-Utailesolo with A (Dec. 22, 2020); Interview by Faaolo Utumapu-Utailesolo with B, in Jet Over Hotel, Salelologa (Dec. 30, 2020).
- 52 Focus group interview with women who are deaf, *supra* note 21.

- 53 Samoa Office of the Ombudsman & National Human Rights Institution, *UN CEDAW Committee: Shadow Report on the Status of Women in Samoa 4* (2018); SUNGO Report, *supra* note 38, at 6-7; Pacific Disability Forum, NOLA, UN WOMEN & Australian Aid, Toolkit on eliminating violence against women and girls with disabilities in Samoa 19 (2019) [hereinafter EAWW Toolkit Samoa] (Two studies in 2017, by the Ministry of Women Community and Social Development and the NHRI (Ombudsman's office) reveal the enormity of the scourge of domestic, gender-based violence within the Samoan family and society. 86% of women (sample 1,880 persons) have been subjected to kicking punching, slapping, causing bodily harm using a hard object. 87% of the women surveyed had experienced threats of physical violence or bodily harm and been subjected to yelling and harsh verbal violence); Spotlight Report, *supra* note 22, at 8 ("The findings of the Samoa Family Safety Survey 2017 show that gender-based violence against women and children continues to increase and abuse affecting the elderly and persons with disabilities is an emerging issue of critical concern. The survey highlighted that 60% of women aged from 20 to 49 years old who were ever in a relationship, had experienced some form of spousal abuse, with 46% having experienced abuse in the last 12 months. High rates of violence were experienced by both boys and girls. Lifetime rate experience of violence was 89% for girls and 90% for boys. The prevalence rate for the last 12 months was 69% for girls and 63% for boys."); UNFPA Samoa Interview, *supra* note 38; Zoom Interview with Mele Maualaivao, Programme Coordinator, UN Women Samoa (July 10, 2020).
- 54 SUNGO Report, *supra* note 38, at 6.
- 55 See UNFPA Samoa Interview, *supra* note 38, at 3; Zoom Interview with Aarni Seger, Disability Focal Point, Nilesh Goundar, Programme Manager, Martin Child, Senior Human Rights Advisor, Pacific Community-SPC, Human Rights and Social Development Division (Oct. 29, 2020).
- 56 EAWW toolkit Samoa, *supra* note 53, at 21.
- 57 *Id.*
- 58 Office of the Ombudsman & National Human Rights Institution, National public inquiry into family violence in Samoa (2018), https://ombudsman.gov.ws/wp-content/uploads/2018/09/National-Inquiry-Report-into-Family-Violence_State-of-Human-Rights-Report-2018-English.pdf. See Interview with A, *supra* note 51; Interview with B, *supra* note 51; Interview by Faaolo Utumapu-Utailesolo with D, in Jet Over Hotel, Salelologa (Dec. 29, 2020); Interview by Faaolo Utumapu-Utailesolo with E, in Nia Mall, Apia (Dec. 22, 2020); Interview by Faaolo Utumapu-Utailesolo with G, in Nia Mall, Apia (Dec. 22, 2020); Interview by Faaolo Utumapu-Utailesolo with H (Dec. 18, 2020); Interview by Faaolo Utumapu-Utailesolo with N, in Nia Mall, Apia (Jan. 27, 2021); Interview by Faaolo Utumapu-Utailesolo with Q, in Nia Mall, Apia (Dec. 15, 2020).
- 59 Min. of Women, Community and Social Development, National Policy on Family Safety: Elimination of Family Violence 2021-2031 7 (July 2021)
- 60 National Policy for Persons with Disabilities, *supra* note 32, at 10.
- 61 Interview with G, *supra* note 58.
- 62 Written Interview with Siliniu Lina Chang, President, Samoa Victim Support Group (SVSG) (Nov. 16, 2020).
- 63 Ombudsman, Persons with disabilities report, *supra* note 19, at 34.
- 64 See Pacific Community-SPC Interview, *supra* note 55; NOLA Interview, *supra* note 36.
- 65 See Women Enabled International, *COVID-19 at the Intersection of Gender and Disability: Findings of a Global Survey* (May 20, 2020), <https://womenenabled.org/blog/covid-19-survey-findings/>
- 66 See Interview with A, *supra* note 51; Interview with B, *supra* note 51; Interview with D, *supra* note 58; Interview with Q, *supra* note 58; Interview by Faaolo Utumapu-Utailesolo with U, in Nia Mall, Apia (Feb. 6, 2021).
- 67 See Focus group interview with women who are deaf, *supra* note 21; Focus group interview with men with disabilities, *supra* note 21.
- 68 See Interview with A, *supra* note 51; Interview by Faaolo Utumapu-Utailesolo with O, in Jet Over Hotel, Salelologa (Dec. 29, 2020).
- 69 Interview with A, *supra* note 51.
- 70 See e.g. Interview with D, *supra* note 58; Interview by Faaolo Utumapu-Utailesolo with L, in Nia Mall, Apia (Jan. 28, 2021); Interview by Faaolo Utumapu-Utailesolo with J (Jan. 27, 2021); Interview by Faaolo Utumapu-Utailesolo with P, in Nia Mall, Apia (Dec. 15, 2020); Interview by Faaolo Utumapu-Utailesolo with T, in Nia Mall, Apia (Dec. 15, 2020); Interview by Faaolo Utumapu-Utailesolo with O, in Jet Over Hotel, Salelologa (Dec. 29, 2020).
- 71 See e.g. Interview with A, *supra* note 51; Interview with G, *supra* note 58; Interview by Faaolo Utumapu-Utailesolo with K (Jan. 27, 2021).
- 72 See e.g. Interview with A, *supra* note 51; Interview with D, *supra* note 58; Interview with E, *supra* note 58; Interview with H, *supra* note 58; Interview with N, *supra* note 58.
- 73 See e.g. Interview with E, *supra* note 58; Interview by Faaolo Utumapu-Utailesolo with I, in Nia Mall, Apia (Jan. 27, 2021); Interview with K, *supra* note 71.
- 74 Interview with U, *supra* note 66.
- 75 Committee on the Rights of Persons with Disabilities (CRPD Committee), *General Comment No. 3 (2016) Article 6: Women and Girls with Disabilities*, para. 27, U.N. Doc. CRPD/C/GC/3 (Nov. 25, 2016). See also UNFPA & WEI, *Women and Young People with Disabilities: Guidelines on GBV and SRHR Services*, *supra* note 6, at 14-15.
- 76 The Policy lists prospective partners as "DFAT...UNICEF, UNDP, UN Women, etc.". UNFPA is not currently listed. National Policy for Persons with Disabilities, *supra* note 32, at 21.

- 77 Inter-Agency Standing Committee (IASC), guidelines on inclusion of persons with disabilities in humanitarian action (2019), <https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/iasc-guidelines>
- 78 Zoom Interview with Tautala Mauala, Secretary General, Samoa Red Cross Society (Aug. 24, 2020).
- 79 NOLA Interview, *supra* note 36; Office of the Ombudsman Interview, *supra* note 19; Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with women who are deaf, *supra* note 21.
- 80 See e.g. Focus group interview with women who are deaf, *supra* note 21; Interview with D, *supra* note 58; Interview with E, *supra* note 58.
- 81 See NOLA Interview, *supra* note 36.
- 82 See NOLA Interview, *supra* note 36.
- 83 See Focus group interview with women who are blind/have physical disabilities, *supra* note 21.
- 84 See e.g. Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Interview with A, *supra* note 51; Interview with B, *supra* note 51.
- 85 See e.g. Focus group interview with men with disabilities, *supra* note 21; Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with women who are deaf, *supra* note 21.
- 86 See e.g. ; Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with women who are deaf, *supra* note 21.
- 87 See e.g. Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with women who are deaf, *supra* note 21; Interview with D, *supra* note 58; Interview by Faalo Utumapu-Utailesolo with M, in Nia Mall, Apia (Feb. 2, 2021).
- 88 See e.g. Focus group interview with women who are blind/have physical disabilities, *supra* note 21.
- 89 *Id.*
- 90 Interview with E, *supra* note 58.
- 91 CRPD, *supra* note 3, at art 23.
- 92 See e.g. Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with women who are deaf, *supra* note 21; Interview with E, *supra* note 58; Interview with H, *supra* note 58.
- 93 See e.g. Focus group interview with women who are deaf, *supra* note 21.
- 94 See e.g. Interview with H, *supra* note 58; Focus group interview with women who are deaf, *supra* note 21.
- 95 See e.g. Focus group interview with women who are deaf, *supra* note 21.
- 96 See e.g. Interview with N, *supra* note 58; Interview with T, *supra* note 70; Focus group interview with men with disabilities, *supra* note 21.
- 97 Samoa Fa'afafine Association, Inc., *Universal Periodic Review Second Cycle - Samoa Submission 1*, <https://www.ohchr.org/EN/HRBodies/UPR/Pages/UPRWSStakeholdersInfoS25.aspx>
- 98 Interview with N, *supra* note 58.
- 99 *Id.*
- 100 *Id.*
- 101 See e.g. Focus group interview by Faalo Utumapu-Utailesolo with women with intellectual disabilities, in the NOLA Conference Room, Apia (Jan. 14, 2021).
- 102 NOLA Interview, *supra* note 36; Goshen Trust Mental Health Services Samoa, *Universal Periodic Review Second Cycle - Samoa Submission 4*, <https://www.ohchr.org/EN/HRBodies/UPR/Pages/UPRWSStakeholdersInfoS25.aspx>
- 103 See e.g. Focus group interview with women who are deaf, *supra* note 21; Interview with D, *supra* note 58; Interview with E, *supra* note 58; Interview with G, *supra* note 58; Interview with H, *supra* note 58.
- 104 See e.g. Focus group interview with women who are deaf, *supra* note 21; Interview with D, *supra* note 58; Interview with E, *supra* note 58.
- 105 See e.g. Interview with D, *supra* note 58; Interview with H, *supra* note 58.
- 106 Interview with G, *supra* note 58
- 107 *Id.*
- 108 Interview with E, *supra* note 58
- 109 NOLA Interview, *supra* note 36.
- 110 See e.g. Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with women who are deaf, *supra* note 21; Interview with G, *supra* note 58.
- 111 Office of the Ombudsman Interview, *supra* note 19.; Ombudsman, Persons with Disabilities Report, *supra* note 19, at 29-30.
- 112 See e.g. Office of the Ombudsman Interview, *supra* note 19; Interview with H, *supra* note 58.
- 113 Office of the Ombudsman Interview, *supra* note 19.
- 114 Interview with H, *supra* note 58.

- 115 See e.g. Focus group interview with rural women with disabilities, *supra* note 46; Focus group interview with men with disabilities, *supra* note 21; Focus group interview with women who are deaf, *supra* note 21; Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with women with intellectual disabilities, *supra* note 101.
- 116 See e.g. Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Interview with L, *supra* note 70.
- 117 See e.g. Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with women who are deaf, *supra* note 21; Focus group interview with men with disabilities, *supra* note 21; Interview with G, *supra* note 58.
- 118 *Id.*
- 119 See e.g. Focus group interview with men with disabilities, *supra* note 21; Focus group interview with rural women with disabilities, *supra* note 46.
- 120 Focus group interview with women who are blind/have physical disabilities, *supra* note 21.
- 121 See UNFPA & WEI, GBV AND SRHR GUIDELINES, *supra* note 6, at 34.
- 122 See UNFPA Samoa Interview, *supra* note 38; SVSG Interview, *supra* note 61.
- 123 NOLA Interview, *supra* note 36.
- 124 See UNFPA Samoa Interview, *supra* note 38; UNFPA, DRAFT - UNFPA PSRO Health Facility Readiness and Service Availability (HFRSA) Assessment Samoa (Dec. 2018).
- 125 See e.g. Interview with E, *supra* note 58; Interview with Q, *supra* note 58; Interview by Faaolo Utumapu-Utailesolo with F, in Nia Mall, Apia (Dec. 22, 2020).
- 126 See e.g. SVSG Interview, *supra* note 62.
- 127 See NOLA Interview, *supra* note 36; Office of the Ombudsman Interview, *supra* note 19.
- 128 See e.g. Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with rural women with disabilities, *supra* note 46; Focus group interview with women with intellectual disabilities, *supra* note 101; Focus group interview with women who are deaf, *supra* note 21; Focus group interview with men with disabilities, *supra* note 21.
- 129 See NOLA Interview, *supra* note 36; Office of the Ombudsman Interview, *supra* note 19; UNFPA Samoa Interview, *supra* note 38; Pacific Community-SPC Interview, *supra* note 55.
- 130 See Pacific Community-SPC Interview, *supra* note 55.
- 131 See Office of the Ombudsman Interview, *supra* note 19; Goshen Trust Mental Health Services Samoa, *Universal Periodic Review Second Cycle - Samoa Submission 2-5*.
- 132 See e.g. Focus group interview with rural women with disabilities, *supra* note 46; Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with women who are deaf, *supra* note 21; Interview by Faaolo Utumapu-Utailesolo with C, in Jet Over Hotel, Salelologa (Dec. 30, 2020); Interview with G, *supra* note 58; Interview with I, *supra* note 73; Interview with J, *supra* note 70; Interview with K, *supra* note 71.
- 133 See e.g. Focus group interview with rural women with disabilities, *supra* note 46; Interview with D, *supra* note 58; Interview with H, *supra* note 58.
- 134 See e.g. Focus group interview with rural women with disabilities, *supra* note 46; Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Interview with F, *supra* note 125.
- 135 See e.g. Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with women who are deaf, *supra* note 21.
- 136 *Id.*
- 137 Focus group interview with women who are blind/have physical disabilities, *supra* note 21.
- 138 See e.g. Focus group interview with women who are blind/have physical disabilities, *supra* note 21.
- 139 NOLA Interview, *supra* note 36.
- 140 See e.g. Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Interview with F, *supra* note 125; Interview with H, *supra* note 58.
- 141 See e.g. Focus group interview with men with disabilities, *supra* note 21; Interview with I, *supra* note 73.
- 142 See NOLA Interview, *supra* note 36; SVSG Interview, *supra* note 62.
- 143 National Policy for Persons with Disabilities, *supra* note 32, at 7; Office of the Ombudsman Interview, *supra* note 19; NOLA Interview, *supra* note 36; Ombudsman, Persons with Disabilities Report, *supra* note 19, at 7.
- 144 See NOLA Interview, *supra* note 36.
- 145 Without further information, it is not possible to verify this finding. However, if this is the case it could speak to the prevalence of NCD risk factors such as alcohol and tobacco abuse as recognized in the National Policy. See National Policy for Persons with Disabilities, *supra* note 32, at 9.
- 146 See Focus group interview with women who are blind/have physical disabilities, *supra* note 21.

- 147 See NOLA Interview, *supra* note 36; Ombudsman, Persons with disabilities report, *supra* note 19, at 39 (“It was observed during home visits with Loto Taumafai that many of the families, particularly with children with intellectual impairments had one or two people within the family who understood (or seem to have some understanding) of the impairment and knew how to care for it. In most cases how they understand the impairment is based on their own understanding but do not fully comprehend the medical condition of the impairment.”).
- 148 NOLA Interview, *supra* note 36.
- 149 *Id.*
- 150 Easy-to-read information (aka as easy-read) is a type of language translation that is clearer and easier to read and understand. It uses common words, short sentences, images and does not use jargon or acronyms. Short sentences are associated with illustrative images to make the meaning as clear as possible. It is a form of translation used to make information accessible to persons with intellectual disabilities. However, it benefits not only persons with intellectual disabilities but also the elderly, non-native speakers, and others. It is a form of translation originally formalized in Europe. For more information, visit <https://www.inclusion-europe.eu/easy-to-read/>
- 151 See e.g. Interview with U, *supra* note 66; Interview with M, *supra* note 87; Focus group interview with women with intellectual disabilities, *supra* note 101.
- 152 Focus group interview with women who are blind/have physical disabilities, *supra* note 21.
- 153 See UNFPA Samoa Interview, *supra* note 38; Focus group interview with women with intellectual disabilities, *supra* note 101.
- 154 See e.g. Zoom Interview with Lealaialoto Liai Iosefa-Siitia, Executive Director, Samoa Family Health Association (SFHA) (July 14, 2020); Focus group interview with women with intellectual disabilities, *supra* note 101; Interview with U, *supra* note 66; Interview with M, *supra* note 87; Interview with E, *supra* note 58.
- 155 NOLA Interview, *supra* note 36; UNFPA, *DRAFT - UNFPA PSRO Health Facility Readiness and Service Availability (HFRSA) Assessment Samoa 18* (Dec. 2018).
- 156 See NOLA Interview, *supra* note 36.
- 157 Ombudsman, Persons with disabilities report, *supra* note 19, at 34.
- 158 *Id.* at 33, 36.
- 159 National Policy for Persons with Disabilities, *supra* note 32, at 17.
- 160 National Policy on Gender Equality, *supra* note 40, at 20.
- 161 Ombudsman, Persons with disabilities report, *supra* note 19, at 34.
- 162 See *Government of Samoa Ministry of Communications and Information Technology, News – Digital information, services and products are accessible by all people, including Persons with Disabilities during COVID-19* (May 14, 2020), <https://mciit.gov.ws/2020/05/14/digital-information-services-and-products-are-accessible-by-all-people-including-persons-with-disabilities-during-covid-19/> (last accessed March 7, 2021).
- 163 SFHA Interview, *supra* note 154; SVSG Interview, *supra* note 62.
- 164 SVSG Interview, *supra* note 61.
- 165 SFHA Interview, *supra* note 154; NOLA Interview, *supra* note 36.
- 166 SFHA Interview, *supra* note 154; SVSG Interview, *supra* note 62.
- 167 SFHA Interview, *supra* note 154.
- 168 SVSG Interview, *supra* note 62.
- 169 Interview with J, *supra* note 70.
- 170 See e.g. Focus group interview with rural women with disabilities, *supra* note 46; Focus group interview with women who are deaf, *supra* note 21; Interview with A, *supra* note 51; Interview with B, *supra* note 51.
- 171 SUNGO Report, *supra* note 38, at 19-20; Focus group interview with women who are deaf, *supra* note 21; Interview with A, *supra* note 51; Interview with B, *supra* note 51; Interview with C, *supra* note 132; Interview with D, *supra* note 58; Interview with E, *supra* note 58; Interview with F, *supra* note 125; Interview with N, *supra* note 58; Interview with Q, *supra* note 58.
- 172 See e.g. Interview with A, *supra* note 51; Interview with B, *supra* note 51; Interview with D, *supra* note 58; Interview by Faalo Utumapu-Utailesolo with S, in *Jet Over Hotel, Salelologa* (Dec. 29, 2020).
- 173 Focus group interview with women who are blind/have physical disabilities, *supra* note 21.
- 174 See e.g. Interview with A, *supra* note 51; Interview with D, *supra* note 58; Interview with I, *supra* note 72; Interview with J, *supra* note 70.
- 175 See e.g. Focus group interview with women who are deaf, *supra* note 21; Interview with D, *supra* note 58.
- 176 Interview with D, *supra* note 58.
- 177 Interview with K, *supra* note 71.
- 178 See e.g. Focus group interview with women who are deaf, *supra* note 21; Interview with A, *supra* note 51; Interview with D, *supra* note 58.
- 179 Interview with C, *supra* note 132.

- 180 See e.g. Interview with A, *supra* note 51; Interview with B, *supra* note 51; Interview with D, *supra* note 58; Interview with E, *supra* note 58; Interview with G, *supra* note 58; Interview with H, *supra* note 58; Interview with P, *supra* note 70; Interview with O, *supra* note 70; Interview by Faaolo Utumapu-Utailesolo with R, in Nia Mall, Apia (Dec. 15, 2020); Interview with S, *supra* note 177; Interview with Q, *supra* note 58; Interview with T, *supra* note 70.
- 181 See e.g. Interview with I, *supra* note 73; Interview with J, *supra* note 70; Interview with K, *supra* note 71.
- 182 See e.g. Interview with P, *supra* note 70; Interview with L, *supra* note 70; Interview with J, *supra* note 70; Interview with I, *supra* note 73; Interview with C, *supra* note 132; Interview with F, *supra* note 125; Interview with E, *supra* note 58; Interview with O, *supra* note 71; Interview with R, *supra* note 180; Interview with Q, *supra* note 58; Interview with T, *supra* note 70; Interview with U, *supra* note 66.
- 183 See e.g. Interview with I, *supra* note 73; Interview with L, *supra* note 70; Interview with C, *supra* note 132; Interview with F, *supra* note 125; Interview with E, *supra* note 58.
- 184 See e.g. Interview with I, *supra* note 73; Interview with L, *supra* note 70.
- 185 See e.g. Interview with A, *supra* note 51; Interview with F, *supra* note 125; Interview with I, *supra* note 73; Interview with J, *supra* note 70.
- 186 Interview with N, *supra* note 58.
- 187 See e.g. Interview with I, *supra* note 73; Interview with J, *supra* note 70; Focus group interview with rural women with disabilities, *supra* note 46.
- 188 See e.g. Focus group interview with rural women with disabilities, *supra* note 46; Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with women who are deaf, *supra* note 21; Focus group interview with men with disabilities, *supra* note 21; Focus group interview with women with intellectual disabilities, *supra* note 101 (interviewees unable to even answer question about family planning); Interview with Q, *supra* note 58; Interview with T, *supra* note 70.
- 189 See e.g. Focus group interview with rural women with disabilities, *supra* note 46. Interview with T, *supra* note 70.
- 190 Interview with B, *supra* note 51.
- 191 See e.g. Focus group interview with women who are deaf, *supra* note 21; Interview with C, *supra* note 132; Interview with E, *supra* note 58; Interview with P, *supra* note 70.
- 192 NOLA Interview, *supra* note 36; Focus group interview with women who are deaf, *supra* note 21.
- 193 See e.g. NOLA Interview, *supra* note 36; Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with women who are deaf, *supra* note 21; Interview with C, *supra* note 132; Interview with H, *supra* note 58; Interview with D, *supra* note 58.
- 194 See e.g. Interview with L, *supra* note 70; Interview with N, *supra* note 58; Interview with I, *supra* note 73.
- 195 See e.g. Focus group interview with men with disabilities, *supra* note 21; Interview with B, *supra* note 51; Interview with G, *supra* note 58.
- 196 See e.g. Interview with A, *supra* note 51; Interview with B, *supra* note 51; Interview with D, *supra* note 58; Interview with E, *supra* note 58; Interview with G, *supra* note 58; Interview with H, *supra* note 58; Interview with N, *supra* note 58; Interview with Q, *supra* note 58.
- 197 See e.g. Focus group interview with women who are deaf, *supra* note 21; Interview with C, *supra* note 132; Interview with E, *supra* note 58; Interview with G, *supra* note 58; Interview with F, *supra* note 125; Interview with H, *supra* note 58.
- 198 See e.g. Interview with C, *supra* note 132; Interview with N, *supra* note 58.
- 199 Interview with R, *supra* note 180.
- 200 Interview with R, *supra* note 180.
- 201 See e.g. NOLA Interview, *supra* note 36; Focus group interview with women who are blind/have physical disabilities, *supra* note 21.
- 202 See e.g. Interview with A, *supra* note 51; Interview with K, *supra* note 71.
- 203 See e.g. Office of the Ombudsman Interview, *supra* note 19; Focus group interview with women with intellectual disabilities, *supra* note 101; Interview with D, *supra* note 58.
- 204 Interview with N, *supra* note 58.
- 205 See e.g. NOLA Interview, *supra* note 36; Focus group interview with women who are blind/have physical disabilities, *supra* note 21.
- 206 CRPD, *supra* note 3, at arts. 9, 12, 22, 25.

- 207 SFHA Interview, *supra* note 154.
- 208 NOLA Interview, *supra* note 36; SFHA Interview, *supra* note 154.
- 209 See e.g. NOLA Interview, *supra* note 36; Focus group interview with rural women with disabilities, *supra* note 46; Focus group interview with women who are deaf, *supra* note 21.
- 210 Interview with D, *supra* note 58.
- 211 Focus group interview with rural women with disabilities, *supra* note 46.
- 212 Focus group interview with women who are blind/have physical disabilities, *supra* note 21.
- 213 Focus group interview with rural women with disabilities, *supra* note 46.
- 214 NOLA Interview, *supra* note 36.
- 215 See e.g. Focus group interview with women who are deaf, *supra* note 21; Interview with D, *supra* note 58; Interview with E, *supra* note 58.
- 216 Interview with E, *supra* note 58.
- 217 Focus group interview with rural women with disabilities, *supra* note 46.
- 218 Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with women who are deaf, *supra* note 21; Interview with H, *supra* note 58.
- 219 See e.g. Focus group interview with women who are blind/have physical disabilities, *supra* note 21; Focus group interview with women who are deaf, *supra* note 21; Interview with H, *supra* note 58; Interview with E, *supra* note 58; Interview with F, *supra* note 125.
- 220 Interview with F, *supra* note 125.
- 221 SVSG Interview, *supra* note 62.
- 222 UNFPA Samoa Interview, *supra* note 38.
- 223 Office of the Ombudsman Interview, *supra* note 19; Pacific Community-SPC Interview, *supra* note 55.
- 224 *Id.*
- 225 Office of the Ombudsman Interview, *supra* note 19.
- 226 UNFPA Samoa Interview, *supra* note 38.
- 227 Interview with K, *supra* note 71.
- 228 *Id.*
- 229 See e.g. Focus group interview with women who are deaf, *supra* note 21; Interview with F, *supra* note 125; Interview with H, *supra* note 58.
- 230 See e.g. Focus group interview with women who are deaf, *supra* note 21; Interview with F, *supra* note 125; Interview with H, *supra* note 58; Interview with I, *supra* note 73; Interview with J, *supra* note 70.
- 231 Focus group interview with men with disabilities, *supra* note 21.
- 232 See e.g. Focus group interview with men with disabilities, *supra* note 21; Interview with N, *supra* note 58; Interview with T, *supra* note 70; Interview with S, *supra* note 177; Interview with Q, *supra* note 58.
- 233 See e.g. Interview with Q, *supra* note 58; Interview with T, *supra* note 70; Interview with P, *supra* note 70; Focus group interview with men with disabilities, *supra* note 21; Focus group interview with women who are blind/have physical disabilities, *supra* note 21.
- 234 SFHA Interview, *supra* note 154.
- 235 NOLA Interview, *supra* note 36.
- 236 Focus group interview with rural women with disabilities, *supra* note 46.
- 237 Focus group interview with women with intellectual disabilities, *supra* note 101.



