

OFFICE OF THE OMBUDSMAN &
NATIONAL HUMAN RIGHTS INSTITUTION



Let's move forward on equality



**STATE OF HUMAN
RIGHTS REPORT:
PERSONS WITH
DISABILITIES**

2016

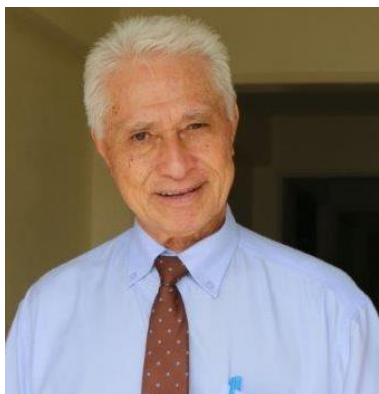
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STATEMENT FROM THE OMBUDSMAN



In accordance with section 40 of the *Ombudsman Act 2013*, it is with great pleasure that I present the second State of Human Rights Report 2016 on the Rights of Persons with Disabilities to the Legislative Assembly and to the people of Samoa. I feel that this is the most fitting time to focus the report on the rights of people with disabilities given that the Government has signed the Convention on the Rights of Persons with Disabilities and has showed commitment to ratify the Convention by the end of this year.

I applaud the Government for steps taken to ensure that the rights of our people with disabilities are further promoted and protected.

The Government of Samoa has made some significant achievements in the past twelve months in the protection and promotion of human rights in Samoa including the rights of people with disabilities. I believe the Government remains committed to human rights and this Office will always seek to work with the Government in strengthening human rights for all Samoans. This report shows how the rights of people with disabilities are currently protected, highlight the gaps, identifies where improvements are required and sets a pathway for strengthening the protection of human rights for people with disabilities in Samoa.

It is my hope that the Government will see it through with the ratification of the CRPD because the ratification will not only bring economic and social benefits to the community as a whole, but will also be a momentous progress for Samoa's continuous realization of human rights.

Soifua ma ia manuia,



Maiava Iulai Toma
OMBUDSMAN

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SUMMARY

In its first State of Human Rights Report, the Office of the Ombudsman—Samoa’s National Human Rights Institute (“the Office”)—identified people with disabilities as a vulnerable population in need of better safeguards for equality, respect and protection. In 2014, the Government of Samoa signed the Convention on the Rights of Persons with Disabilities (“CRPD”) and has indicated its intention to ratify it at the end of the year. Given this commitment, the Office decided to focus its second State of Human Rights Report on the rights of Samoa’s people with disabilities in order to support the Government’s decision and facilitate the ratification process.

As such, the report comprehensively breaks down the issues and is organized into six major parts. It (1) begins with an overview on the state of human rights in Samoa, including the progress made since the last reporting period; (2) discusses the aim of the report and its methodology; (3) provides an introduction on the topic of disability, defining disability both within the Samoan context as well as in relation to the CRPD; (4) analyses the current situation for people with disability in Samoa, focusing on hard-hitting issues like health, education and employment and brings to the forefront matters of accessibility and raising awareness; (5) gives an overview of the three main economic considerations for Samoa in ratifying and implementing the CRPD—the economic empowerment of people with disabilities as well as their families—and argues for this to be the deciding factors for ratification of the Convention; and (6) offers a table of recommendations based on the issues raised.

While the report covers many aspects of the protection and promotion of the rights of people with disabilities, this Summary highlights the most *critical issues* and identifies the largest gaps for the Government to address as it prepares for ratification of the CRPD. They are stated in recommendation form and are as follows:

1. Complete a legislative compliance review
2. Raise awareness on the rights of people with disabilities
3. Improve Health services
4. Provide for Inclusive Education
5. Employ people with disabilities

What is disability?

Various lenses in the way disability is defined have evolved overtime to assist in understanding the definition of disability and what it involves. Traditionally, disability have been recognized and associated with the medical approach which solely focuses on the individual’s impairment (the condition of the body or the mind) as an illness that can be cured by medical professionals. Overtime this viewpoint has develop into the *social model* approach where rather looking at the impairment as an illness it focuses on the combination of the impairment and the barriers such as no ramps, inaccessible information etc which exist in society that prevents people with disabilities from being able to participate fully.

The *human rights* approach builds on the same principle of the social model and further recognises barriers in society as acts of discrimination to the full participation of people with disabilities. This approach seeks to support and respect disability as another form of diversity that they are also human beings with human rights just the same as people without disabilities.

Thus, it is the view of the Office that any definition to be adopted in Samoa should therefore reflect the *human rights based approach* as emphasized in the Convention:

*“People with disabilities **include** those who have long-term physical, mental, intellectual or sensory **impairments** which in **interaction** with various **barriers may hinder their full and effective participation** in society on an equal basis with others.”*

Disability in the CRPD in the Samoan Context

Strengthening human rights for all Samoans must include improving the protection of the rights of people with disabilities. For Samoa, this means strong support must be given to the family unit, as traditionally the main protection and care for the wellbeing of people with disabilities has always been the exclusive responsibilities of the families themselves. Families, care and provide for the needs of their family member(s) with a disability, within their means and to the best of their understanding. Families as well as the community (to some extent), show the *Fa'asamoa* principle of love, protection and respect to people with disabilities through the sharing of food, giving assistance in crossing the road, entering or exiting a building, and receiving or giving information.

A caring attitude towards a person with disability is still instinctive in Samoa and this report highlights how this can unconsciously create a barrier for a person with a disability to gain full participation in society, especially with regards to gaining access to education and employment—two of the largest gaps that exist. As such, efforts to support the empowerment of people with disabilities—particularly in relation to the five issues raised above—in enjoying their rights under the CRPD must be accompanied by robust awareness raising programs targeting the family and community levels in order to provide for successful implementation and fulfilment of obligations under the CRPD once it is ratified.

The Government has had minimal direct financial involvement in providing support for people with disabilities and their families. This may be a result of a reliance on the role of *Fa'asamoa* in looking after people with disabilities. It is no revelation that people with disabilities have been cared for by their family members and with the assistance of non-governmental organizations (“NGO”). Over many years, the provision of services for disabilities has been primarily provided by NGOs with the financial assistance of international donors and minimum financial support by the Government.

Currently, the coordination of Disability Programs in Samoa, which includes activities and services, is largely funded by international donors, particularly by the Australian Government through the *Samoa Disability Programme (“SPD”) 2013-2017*. With the ratification of the CRPD, the Government will assume responsibility to care for and assist people with disabilities in Samoa, such as funding disability-related services.

Raise Awareness on the Rights of People with Disabilities

Awareness raising and education is vital in realising the rights and meeting obligations under various international treaties, including the CRPD. Awareness raising like trainings that address stereotypes, prejudices and stigma can serve as an implementation measure to educate people as to the definition of disability—the interaction between impairment and unwelcoming environment including physical, inaccessible information and attitudes in society—and how to overcome negative attitudes towards it. Specifically in terms of empowerment via inclusive education and employment, training that targets family members of people with disabilities is crucial in order to foster greater understanding and awareness as well as provide better assistance and services to relatives of people with disabilities.

Throughout this report, the critical role of the family is emphasized as the way in which families care for their relatives with disabilities affects (to some extent) the realisation of the rights of people with disabilities. In realising the significance of their role, it is the view of the Office that attention must be given to the education of families in respecting, protecting and promoting the rights of people with disabilities. A strong support of the family unit will assist Samoa in the implementation and fulfilment of its obligations under the CRPD. It may be fruitless for the Government to provide access to education and employment and other services when families themselves place no value on the exercising their relatives’ rights.

Complete a Legislative Compliance Review

Prior to ratification, it is important to complete a legislative compliance review (“LCR”) in order to harmonize Samoa’s legislations with the rights and obligations under the CRPD. The Government is in the process of completing the LCR however, it has yet to be completed at the time of this report’s publication. This Office recommends that the Office of the Attorney General (“OAG”), the Ministry of Women, Community and Development (“MWCSO”) and the Samoa Law Reform Commission (“SLRC”) complete this as a collective effort

Furthermore, the Government’s decision to undertake a cost/benefit analysis to determine overall feasibility of Samoa’s ratification of CRPD can be helpful in terms of financial planning, it should not form part of the ratification decision making process. Assessing ratification and implementation costs in the case of the CRPD can be a useful exercise as it can show the direct costs of disability and help policymakers better identify the specific needs of people with disabilities and their households. However, the Cost Implementation plan simply focused on the overall monetary value that it was going to cost the Government to implement the CRPD but did not include a benefit analysis, which may not be a fair representation of what a cost/benefit analysis is.

Improve Health

The CRPD requires government to provide free or affordable health care to ensure that people with disabilities are able to make independent and informed decisions about their health. This right is closely linked to the right to habilitation and rehabilitation. It requires the State to provide a range of health services including allied health services such as physiotherapist, speech pathology, occupational therapy etc, who will provide input and advice on the rehabilitation process. Village consultations and home visits showed that people with disabilities and families with people with disabilities are paying for medication and health related services. This is despite the fact that on the National Health Services (“NHS”) website it states that people with disabilities receive free health care. Participants further raised concerns that the cost of health care has a disproportionate effect on people with disabilities and their families as they often need to see doctors and health professionals much more regularly than people without disabilities.

The state of allied health care and the provision of multi-disciplinary health services in Samoa is poor. There are currently very few local allied professionals in Samoa. There are two Australian allied health volunteers (speech pathology and occupational therapy) who are currently engaged with NHS to develop and define the roles and responsibilities of these services. In other cases, the NGOs such as Loto Taumafai and Samoa Victim Support Group (“SVSG”) provide, within their resources and skills, rehabilitation and habilitation.

Psychosocial disabilities or mental disability are included in the definition of ‘disability’ within the CRPD where it states that “people with disabilities include those who have long-term physical, *mental*, intellectual or sensory impairments.” However, many people in Samoa do not consider psychosocial as a disability- they described all forms of psychosocial disabilities as simply ‘brain fever’ or the person being “possessed with demons.” Many families do not know how, or do not have the support, to look after their relatives who have psychosocial impairments. The *Samoa Mental Health Policy 2006* highlighted the challenges faced by the Mental Health Unit at that time such as the lack of psychiatrists as they have been coming and going over the years, the lack of medicine and proper facilities (such as space to keep patients, psychiatric beds, etc). Some of the patients which are diagnosed by the Mental Health Unit are referred to the Goshen Trust Mental Health Services Samoa (“Goshen Trust”) which provides respite care for these patients. However, no funding is provided by the government to Goshen Trust so that they can provide these services.

There were other concerning issues raised such as: (a) the lack of early intervention and detection. The consultations and home visits highlighted that there are no adequate early detection and intervention systems in Samoa. The responses from the community consultations noted that babies (in early stages

of life) who suffer fits, fever, cold and who were taken to the hospitals were commonly diagnosed with brain fever (*fiva faiai*). In other cases, the disabilities were seen by the family as a result of the will of God, or punishment for the sins and misdeeds of family members. In other cases, families do not have the financial means to take the babies to the hospital. For these reasons, the babies are not taken to the hospital and consequently, these children are sometimes not diagnosed at all; and (b) lack of proper diagnosis. The community consultations and home visits highlighted that one of the biggest barriers that currently exist for people with disabilities in Samoa, is that disability itself is not being properly diagnosed. Many people with disabilities in Samoa go undiagnosed or do not get their disability properly diagnosed. In other cases, the home visits demonstrated that the lack of proper or incorrect diagnosis have resulted in families doubting and mistrusting the health professionals and has discouraged them from seeking further necessary medical attention for their relatives.

Provide for Inclusive Education

One of the major concerns that came out during home visits was that out of 120 families the Office visited, about 90% of the children with disabilities did not attend school and were kept in the home instead. The realisation of the right to education is a pre-requisite to leading a dignified and successful life and Article 24 of the CRPD which ensures that people with disabilities participate and become inclusive in the general education system together with people without disabilities. Currently, Samoa has a segregated or dual-education system where special schools, such as Loto Taumafai and Aoga Fiamalamalama, exist for children with disability. As such, it appears that the reality of the Samoan education system is not an inclusive system but that of an integrated system. Whereas *integration* requires a child to adjust to an education system, *inclusion* is about making the system adapt to each child.

Samoa has passed the *Education Act 2009* (“Education Act”) which recognizes and allows for the inclusive education and in support of this, the Ministry of Education, Sport and Culture (“MESC”) developed and finalised in principle the *Inclusive Education Policy for Students Living with Disabilities (“IEPSLD”) 2014*. Furthermore, the MWCSO, in its *National Policy for Persons with Disabilities (“NPPD”) 2016-2020*, also highlighted the importance of inclusive education and the mechanisms for combating barriers associated with it. Through the consultations with MESC, the Ministry noted that the reasons attributed for the lack of success in the implementation of the *IEPSLD* is because it lacks the necessary capacity and expertise to coordinate the implementation of it. There is a need for MESC, in particular the Inclusive Education Unit within the Curriculum Division, to spearhead not only the Strategic Plan but also to work with the current service to ensure that students with disabilities have their needs fully met.

Employ People with Disabilities

The right to employment is similar to the right to education, in the sense that it has long been recognized as a basic human rights and Article 27 of the CRPD has expanded this right to allow people with disabilities to have access to open, inclusive and accessible employment in the mainstream labour market. Samoa has already passed the *Labour and Employment Relations Act 2013* (“LER Act”) that prohibits anyone from discriminating against people with disabilities, whether they are applying for a job if they are a current employee. However, this does not apply to the public service and should therefore be expanded. Further, the *Labour and Employment Relations Regulations 2015* (“LER Regulations”) recognize the rights of people with disabilities and require the employer to modify the facilities to meet the needs of the people with disabilities if it is reasonable in the circumstances to do so. The Employment Regulation goes on to state that it is an offence if an employer contravenes this obligation.

The *NPPD 2016-2020*, noted that from the *Labour Force Survey 2012* (“Labour Force Survey”) there are an estimated total of 2,750 employed people with disabilities or 24% of the total work force. It should be noted at this stage, that these figures do not represent a true reflection of the actual numbers of people with disabilities who are employed in the labour market. This discrepancy may be attributed

to physical and attitudinal barriers of employers. Employers assume that people with disabilities may not have the capacity to perform the work. Furthermore, the inaccessibility of workplaces, the unavailability of information and communication in the appropriate form and the lack of transportation may also limit people with disabilities from finding suitable jobs and taking advantage of educational and training or commuting to facilities of all types.

There is a lack of data to provide a true reflection of the actual numbers of people with disabilities in the labour force. Accordingly, the Ministry of Commerce, Industry and Labour (“MCIL”) should carry out an extensive survey to verify the number of people with disabilities who are employed in the work force and their impairments. This will determine the *reasonable accommodations* to be made and by whom. Reasonable accommodation is assistance or changes (removal of barriers), for example, to a workplace, that will enable an employee to do his or her job despite having a disability. The CRPD provides that the cost (financial or otherwise) of the removal of the barrier should not impose an undue burden on the person having to remove the barrier. In the Office’s last report, it stated that despite the equal opportunity made available by MCIL to people with disabilities to access their jobs and apprenticeship programmes, there were no efforts made to cater to the specific needs of people with disabilities. There are still no efforts. The CRPD calls for Government to ensure that people with disabilities have effective access to general technical and vocational programmes, services and training. As such MCIL should review the accessibility of their vocational training programmes in order to make them inclusive.

CONCLUSION

The Office highly commends the collective efforts by the Government, civil society and development partners/donors regarding the progress made to ensure the participation and enjoyment of rights for people with disabilities are addressed. Naturally, more needs be done to ensure that such efforts resonate at all levels of society from the family level to the political one. It is hoped that this report can spur action in this regard, particularly considering that people with disabilities were included in all stages of its preparation and submission, because ratification of the CRPD will not only bring economic and social benefits to the community as a whole, but will also be a momentous progress for Samoa’s continuous realization of human rights and will.

CRITICAL RECOMMENDATIONS

Critical Issue	Recommendation	Responsible Party	Timeframe (to action recommendation)
LCR	1) Complete the LCR and ensure that it fully harmonises all of Samoa's laws with the CRPD.	OAG, SLR and MWCSO	Before ratification of CRPD
Health	2) People with disabilities should have access to free or affordable health care in Samoa via the implementation of a subsidy card for people with disabilities.	NHS & MOH	Within a year from ratification of CRPD
	3) Develop a Strategic Plan to increase allied health services and undertake awareness raising activities in schools promoting the roles of allied health professionals.	NHS & MOH	Within a year from ratification of CRPD
	4) The <i>Mental Health Act</i> should be amended so that it is compliant with the CRPD.	NHS and OAG	Before ratification of CRPD
	5) Funding should be provided to the Goshen Trust so that Goshen Trust can adequately provide services for people with acute psychosocial disabilities.	MOF, MOH and NHS	Initiate discussions for the provision of budget in the next financial year (2017-2018)
Education	6) Prioritise preparing an Action Plan of how to achieve the IEPSLD including: (i) set realistic timeframes; (ii) identify the budget, (iii) how to raise the capacity of the personnel (ie: the current teachers, teacher aides, student teachers), (iv) reasonable accommodation through the universal design of educational facilities; (v) support measures (such as the appropriate curriculum, assessment and test criteria, teaching in the appropriate method through Braille, electronic readers, sign language);	MESC	Initiate discussion immediately and implement within year from ratification of CRPD
	7) Develop the current inclusive education course within NUS into a full program, and provide initiatives to encourage students to undertake this profession.	MESC & NUS	Initiate discussion immediately and implement within year from ratification of CRPD

	8) The Inclusive Education Unit within MESC should be activated and strengthen to implement the IEPSLD in coordinating with the service providers.	MESC	Immediate
Employment	9) An extensive survey should be carried out to obtain disaggregated data on the number of people with disabilities who are employed to ensure their needs are catered for.	MCIL and PSC in collaboration with SBS should carry out	Initiate discussion immediately and implement within year from ratification of CRPD
	10) Efforts must be improved in creating job opportunities for people with disabilities through awareness within the public and private sector focusing on the benefits of employing of people with disabilities.	MCIL & PSC	Immediate
Awareness-raising	11) Efforts should be increased in raising awareness within the family unit about the rights of people with disabilities.	NOLA in collaboration with MWCSO and the community networks (e.g STN, SN, Youth and Church)	Immediate
	12) More awareness raising activities should be carried out to promote the capabilities of people with disabilities in the employment sector and the contribution they can make in the development of their communities.	MCIL, PSC, MWCSO, in collaboration with NOLA and Chamber of Commerce	Immediate
	13) All schools should be covered in the awareness programs that targets children and teachers.	NOLA in collaboration with MESC	Immediate

ACRONYMS

APTC	Australia-Pacific Technical College
CED	Convention for the Protection of All Persons from Forced Disappearance
CEO	Chief Executive Officer
CRC	The Convention on the Rights of the Child
CRPD	The Convention on the Rights of Persons with Disabilities
DFAT	Department of Foreign Affairs and Trade of Australia
DHS	Demographic Health Survey
DMO	Disaster Management Office
IEPSLD	Inclusive Education Policy for Students Living with Disabilities
ICCPR	The International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ILO	International Labour Organisation
ICT	Information Communication Technology
ICCPR	International Convention on Civil and Political Rights
LCR	Legislative Compliance Review
LER Act	Labour and Employment Relations Act
LER Regulation	Labour and Employment Relations Regulations
LTA	Land Transport Authority
MCIL	Ministry of Commerce, Industry and Labour
MCIT	Ministry of Communication, Information and Technology
MESC	Ministry of Education, Sports and Culture
MJCA	Ministry of Justice and Court Administration
MNRE	Ministry of Natural Resources and Environment
MDS	Mobility Device Service
MOH	Ministry of Health
MOP	Ministry of Police
MWCSD	Ministry of Women, Community and Social Development
MWTI	Ministry of Works, Transport and Infrastructure
NBC	National Building Code
NDMP	National Disaster Management Plan
NGO	Non-Governmental Organisation
NHRI	National Human Rights Institution
NPPD	National Policy for Persons with Disabilities
NOLA	Nuanua O Le Alofa
NUS	National University of Samoa
NHS	National Health Service
NYC	National Youth Council
OAG	Office of the Attorney General
OEC	Office of the Electoral Commission
OTR	Office of the Regulator
PSC	Public Service Commission
PUMA	Planning and Urban Management Agency

SBS	Samoa Bureau of Statistics
SDP	Samoa Disability Program
SDPR	Samoa Disability Prevalence Report
SIEDP	Samoa Inclusive Education Development Program
SLRC	Samoa Law Reform Commission
SN	Sui o Nuu
SPCS	Samoa Prisons and Correctional Services
STN	<i>Sui Tamatai o Nu'u</i>
SVSG	Samoa Victims Support Group
TSP	Transport Sector Plan
UDHR	The Universal Declaration of Human Rights
UN	United Nations
UPR	Universal Periodic Review
WHO	World Health Organisation

PART 1: STATE OF HUMAN RIGHTS IN SAMOA

1. Progress since the last reporting

The Office commends the Government, relevant stakeholders, development partners and NGOs for various programs and policies produced over the past twelve months in the effort to continue to promote and protect human rights in Samoa. The following are some of the highlights of these programs and policies:

- a) The submission of Samoa's second Universal Periodic Review ("UPR") to the United Nations ("UN") Human Rights Council. This report was reviewed on the 3rd of May 2016¹ and was well received by the Human Rights Council, particularly the establishment of the NHRI. Samoa accepted 91² out of 129 recommendations of the concluding observations including the ratification of the CRPD and all recommendations in the Office's first State of Human Rights Report 2015.³
- b) The ratification of two Optional Protocols to the Convention on the Rights of the Child ("CRC"): (i) Optional Protocol to the CRC on a Communications Procedure and the (ii) Optional Protocol to the CRC on the Sale of Children, Child Prostitution and Child Pornography.⁴
- c) The submission of Samoa's combined second-fourth report to the UN CRC Committee. This periodic report was reviewed on the 17th to the 18th of May 2016.⁵
- d) The signing of the CRPD in 2014 and the commitment to ratify the CRPD. There have been many programs and activities towards the ratification.
- e) Continuing training and competition/ awareness-raising programs on the promotion and protection of human rights specifically to women, children and people with disabilities.

The Office encourages the Government to continue to comply with its reporting obligations as required under each convention it has ratified.⁶ However, there are two outstanding reports on which Government is yet to make its initial reporting since their ratification: the International Convention on Civil and Political Rights and the Convention for the Protection of All Persons from Forced Disappearance.

It is important to note that not only does the Government need to submit these reports, it is also required to implement and follow up on the concluding observations after each review before the next reporting is due. It is anticipated that with the new reporting and implementation mechanism that is currently being established by Samoa's UPR Taskforce in collaboration with the Office of the High Commission of Human Rights in Fiji, that future reporting and implementation process for Samoa would be well facilitated and coordinated.

2. First State of Human Rights Report 2015

The Office prepared and submitted to Parliament its first State of Human Rights Report 2015 "*For Samoa, By Samoa*" on the 30th of June 2015. It provided a synopsis of the prevalent human rights issues including the rights of children, women, people with disabilities, prisoners as well as health,

¹ See <http://www.ohchr.org/EN/HRBodies/UPR/Pages/UPRMain.aspx>. Accessed 22 May 2016.

² Samoa has until September to make known to the Human Rights Council whether it chooses to implement the remaining 38 recommendations. United Nations Draft Report of the Working Group on the UPR-Samoa, 25th Session. A/HRC/WG.6/25/L.3, 9 May 2016 at pg 9.

³ See United Nations Draft Report of the Working Group on the UPR-Samoa, 25th Session. A/HRC/WG.6/25/L.3, 9 May 2016.

⁴ Effective 29 April 2016. See <https://treaties.un.org/doc/Publication/CN/2016/CN.378.2016-Eng.pdf>. Accessed 22 May 2016.

⁵ See <http://www.ohchr.org/FR/NewsEvents/Pages/DisplayNews.aspx?NewsID=19936&LangID=E>. Accessed 22 May 2016.

⁶ For instance the CEDAWCRC, ICCPR and CED. http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Treaty.aspx. Accessed 22 May 2016.

religion and environmental health. The report identified actions carried out by the Government to ensure that rights of these individuals and groups were protected. It also highlighted several emerging issues and made a number of recommendations. The report to date has yet to be discussed and debated by Parliament as required by law. The Office strongly urges the Government to pursue the consideration of the report in accordance with section 40 of the *Ombudsman Act 2013* and address the recommendations provided in the report.

PART II: INTRODUCTION

1. Why focus on Disability?

“I am 40 years old. I have a physical impairment in my legs. I try to get involved in village activities (aumaga) when I can. The village men don’t let me participate in many of the activities because of my condition. And it makes me sad.”

“I am mute. I love carpentry. I want to go to school to learn carpentry but there is no school like Loto Taumafai in Savaii.”

“I have visual impairment. It is difficult for me to move around especially with the public transportation. I cannot see and know the buses arrive or the destinations I am travelling to.”

The disability data collected during the most recent *Demographic Health Survey* in September 2014,⁷ showed that the prevalence of disability among adults aged 18 and older in Samoa is 15.7%.⁸ The prevalence of disability for children aged 2-4 is 9.1%,⁹ while for children aged 5-17 is 4.8%.¹⁰

Considering the prevalence rate of disability in Samoa, the Office supports the initiative by the Government and NGOs to push for the ratification of the CRPD to further protect the rights of people with disabilities. Therefore, the Office has decided to focus its second State of Human Rights Report on the Rights of Persons with Disabilities. The first State of Human Rights Report 2015 identified people with disabilities as one of the most vulnerable populations requiring increased safeguards for equality, respect and protection. This report explores the human rights issues of people with disabilities in more depth to assist Samoa as it looks through its Government to ratify the CRPD.

This report will:

- a) summarise some of the main obligations of government under the CRPD;
- b) provide a brief analysis of the current status of how the rights of people with disabilities are recognised and protected;
- c) identify gaps which need to be addressed in order for Samoa to be compliant with its obligations upon ratification of the CRPD;
- d) portray the understanding and awareness of people on the rights of people with disabilities; and
- e) advocate for the voices of people with disabilities on the issues concerning them.

Given the capacity of the Office, this report is not a comprehensive analysis of all the Articles and obligations in the CRPD, but it seeks to highlight the guiding principles advocated and promoted in the CRPD.

⁷ The Survey involved questions for adults which were tested by the UN Washington Group on Disability are internationally recognised standard for disability identification for the purposes of population based analysis. These questions identify people with basic activity limitations that put them at risk of being excluded from society because of barriers in the environment.

⁸ The Office has decided to use the less conservative measurement for prevalence of disability. This means that 15.7% of survey participants experienced some difficulty in at least on one of the following domains: seeing; hearing; walking or climbing steps; remembering or concentrating; difficulty in looking after themselves; and difficulty in communicating.

⁹ This is the less conservative measurement for prevalence for children aged 2-4 which reflects children experiencing at least “some difficulty” in or more of domains.

¹⁰ This is the less conservative measurement for prevalence for children aged 5-18 which reflects children experiencing at least “some difficulty” in or more of domains.

2. Methodology

This report adopted various methods of collecting data and information in an effort to ensure it was as inclusive and participatory as possible. The various methods used were:

- a) Public consultations with all relevant stakeholders to obtain their input, in particular what identified as significant issues of concern and recommendations to be included in this report. These consultations included NGOs,¹¹ development partners, the Human Rights Advisory Council¹², and relevant Government Ministries.¹³
- b) The Human Rights Survey 2016 ('the Survey') conducted by the Office sought views of the public on the rights of people with disabilities.¹⁴ A total of 537 survey questionnaires were collected from 32 schools and 935¹⁵ questionnaires from the public (including 98 villages). The age range of participants in the surveys was from 10 to 74 years.
- c) Village Consultations, focus groups¹⁶ (involved in the Survey) and interest groups¹⁷ who provided clarification on the Survey questions during the consultations where participants were split up according to the following categories: women, men and youth.¹⁸
- d) Case Studies collected from home visits (with people with disabilities)¹⁹ to give voice to the actual experience of people with disabilities and their families/carers. A total of 120 families were visited and a total of 50 one-on-one interviews were carried out with people with disabilities, their sole carers and family members.²⁰
- e) Specific data on relevant issues was also requested from consulted stakeholders.

This report is not a completely balanced representation of the population as there were more participants in the rural consultations than in the urban consultations. The results of the Survey undertaken by the Office although it included both rural and urban villages, showed that the rural population is overly represented in the data.

Quotes and Case Studies

All the quotes and case studies in this report are derived from the Office's consultations and home visits. Details of some of the quotes and case studies have not been identified to protect the privacy of the participants.

Recommendations

Recommendations for Government's consideration, debate, endorsement and implementation follow the analysis of each CRPD right.

¹¹ The first phase of consultations began with consultations with all NGOs working in the area of disability. A full listing of NGOs consulted *See* Annex A.

¹² The Human Rights Advisory Council is a pluralist representation of civil society that brings the Office into compliance with the 'Paris Principles' for NHRIs.

¹³ Government Ministries were in the third phase of consultations. *See* Annex A for a full listing of Government ministries consulted.

¹⁴ There were two versions of the survey used in the process: the School Survey was designed for school children aged 10 – 13 years old which contained 7 questions and the Survey consisted of 21 questions completed by adults and school aged students from 14- 18. *See* Annex B for copies of these surveys.

¹⁵ A gender breakdown of 45% male and 55% female for the Survey only as the School Survey was not disaggregated by gender. There were 55 people with disabilities who completed the Survey.

¹⁶ For a full listing of villages and interest groups that participated in focus groups, please *see* Annex A.

¹⁷ Interest groups include the Samoa National Youth Council.

¹⁸ Where feasible, this was the breakdown of the focus groups. Due to human resource constraints, some villages were simply divided into male and female focus groups.

¹⁹ Consultations with NGOs helped identified possible case studies and it informed home visits with Loto Taumafai and Special Olympics Samoa during their regular visits to people with disabilities in their services. These home visits gave the office a firsthand observation to the real situation of the lives of people with disabilities in Savaii and Upolu.

²⁰ The identities of some of the families and individuals that were interviewed and wished to keep their identity confidential will be kept confidential throughout this report. Qualitative data and case studies were guided by 5 questions. These visits were carried out with the approval and support of Loto Taumafai and Special Olympics. Copy of the Survey attached as Annex B.

PART III: WHAT IS DISABILITY?

1. Defining Disability

The different approaches in defining disability which currently exist around the world are discussed below to assist in understanding how the definition of disability has evolved to what it is now.

Medical Approach

Traditionally, people with disabilities have been recognized and associated with the medical approach of disability which focuses on the individual person's impairment. Impairment relates to a condition of the body or the mind, such as not being able to walk, see, hear or having difficulty in understanding. The impairment is seen as an 'illness' or 'sickness' which needs to be 'fixed' through medication or rehabilitation in order to be 'normal'. The medical model focuses on finding an appropriate cure for the impairment. As a result, the voices of people with disabilities are often overlooked in the attempt to cure the impairment²¹ as medical professionals (including doctors, psychiatrist and nurses) have great control over their lives.

Social Model

Over time the medical model of disability has evolved into the *social model*. This model focuses on the combination of the impairment and the barriers which exist in society that prevent people with disabilities from being able to participate in society, as highlighted below:

$$\text{IMPAIRMENT} + \text{BARRIER} = \text{DISABILITY}$$

A common example is a child who is unable to walk, who uses a wheelchair and is unable to enter a school building because there are no ramps. The child's inability to walk is the impairment and the barrier is the lack of accessible ramps which would allow him/her to access the school building.

$$\text{INABILITY TO WALK (Impairment)} + \text{NO RAMPS (Barrier)} = \text{DISABILITY}$$

The intention of the social model is to ensure that barriers which exist in society are either removed, modified or altered to enable the person with the impairment to participate in society and enjoy society on an equal basis with people without disabilities.²² The following are examples of the different types of barriers to accessibility for people with disabilities.

Type of Barrier	Explanation
<i>Physical</i>	The most obvious barriers include the lack of wheelchair access to buildings (eg: homes, churches, hospitals and place of employment); transport such as buses with no ramps or hand rails; inaccessible roads and curbs which make it hard for people in wheelchairs and with walking aides to navigate around the village or town, or appropriate lighting for people with visual impairments so that they may be able walk on streets and in buildings with confidence.
<i>Informational</i>	The lack of access to information is one of the biggest barriers that people with disabilities face every day. Examples of informational barriers include when a television program does not have captions or a sign language interpreter for people with hearing impairment, or a person with a visual impairment cannot read the information on a website because the website does not have the proper

²¹ The Convention of the Rights of People with Disabilities 'Training Guide, Professional Training Series No.19, United Nations of the Office of the High Commission, at pg 9.

²² See *Ibid* 30 below.

	accessible software such as electronic audio readers in order to read the information.
Formal	Includes legislations, policies and practices that are in place that prevent or fail to assist access for people with disabilities. For instance, there is no mandatory provision in Samoa for voting papers to be scribed in braille to allow or assist a person with a vision impairment to exercise their right to vote and participate in political matters or where there is no anti-discrimination law which prevents people with disabilities from being discriminated against in relation to not being able to access a building or aeroplane.
Attitudinal	Is the negative attitudes and lack of understanding of disability issues. Sometimes there are negative stereotypes surrounding people with disabilities, such as the perception that there is something ‘wrong’ with people with disabilities or ensuring that people with disabilities enjoy equality is not a high priority. If people do not think equal access is an important issue then it will be difficult to remove the other barriers listed above.

Human Rights based approach

The *human rights approach* is now considered as the appropriate model for the protection of the rights of people with disabilities. The human rights model does not take pity on people with disability, rather, it seeks to support, respect and celebrate disability as another form of diversity so that people with disabilities can participate in society, in the workplace, in education, in political and cultural life and defend these rights by accessing justice.²³ Further, this approach builds on the social approach by acknowledging that people with disabilities have human rights just the same as people without disabilities. It treats barriers in a society as discriminatory and provides a system whereby people with disabilities can raise their concerns relating to the barriers which prevents their full participation in society.²⁴

Disability in the Samoan context

Fa’asamoa or the Samoan way of life is underpinned by core values of love, protection and respect. One of the most important aspects of the *Fa’asamoa* is the family. This can be best summed up by the Samoan saying “O le tagata ma lona faasinomaga po’o le tagata ma lona aiga”- One’s sense of identity and belonging revolves around one’s family. One’s family comes above all else and one would do anything for their family. In addition, a prominent feature of *Fa’asamoa* is the responsibility of “tausi aiga” or tausi matua” (or family carer) instilled in every Samoan to care for their elders, children and ill relatives which traditionally includes people with disabilities. This perception is verified in the Survey and focus group discussions where 96%²⁵ of the total surveyed participants agreed that *Fa’asamoa* significantly influences the way Samoans care and treat people with disabilities.

“It is the responsibilities of families to care for their children and our elders. These are our cultural responsibilities and duties.”

Traditionally, the protection and caring for the wellbeing of people with disabilities in Samoa has always been the exclusive responsibilities of the families themselves. Families within their means and to the best of their understanding, care and provide for the needs of their family member(s) with a disability. The care provided by the families includes (but is not limited to) feeding, bathing, clothing and to an extent make decisions for them – such as whether or not to attend school, work, vote, have

²³ The Convention of the Rights of People with Disabilities ‘*Training Guide, Professional Training Series No.19*, United Nations of the Office of the High Commission, at pg 10.

²⁴ See *Ibid* 32 below.

²⁵ See Survey attached as Annex B.

a family and participate in village activities. Such care is a reflection of the *Fa'asamoa* principle of love and protection. The deep rooted sense of love and responsibility to take care of a person with a disability may stem from the perception that:

- a) it is in the best interest of the person with a disability as they are unable to do it for themselves;
- b) sacred duty for families to care for a person with a disability because it is a source of blessing; and
- c) for the protection of the person with a disability in case they hurt themselves if they try to do things on their own or prevent being hurt by others (such as a female being taken advantaged of).

The community demonstrates concern and respect through the sharing of food, giving assistance in crossing the road, entering or exiting a building, and assisting with receiving or giving information to people with disabilities. It is common to still see respect shown to a person with a disability by giving him or her priority by way of seating in the church or on the bus or when waiting in line to see a doctor.

L is 32 years old and has cerebral palsy. "My full time job is moving him around, feed, shower etc...he became too heavy to carry to the bathroom so he now wears a diaper...most times he wants to go outside but I don't allow him because he may catch disease from others and make him even more sick, so we just put him on his wheelchair and face him to the road to watch passers walking by, he enjoys doing that..."

"We don't allow her to go outside unless someone accompanies her. The only time she goes is to Sunday school, however, either I go with her or our other family member takes her...we are very protective of her because she is a girl and bad people normally takes advantage of girls like Y...I understand that she is an adult now and her feelings are becoming like ours but her brain is of a child, she doesn't know what is best for her so we do our best to protect her..."

A caring attitude towards a person with disability is still instinctive in Samoa and may be recognized as a charity approach. It may also reflect the medical approach²⁶ as the families focus on caring for the person because of his or her impairment. During the consultations, the Office observed many people in the community refer to people with disabilities as "tagata ma'i or le au mama'i", a sick person or sick people. Samoan terminology and expressions show that people view and understand disability as sickness, illness or something 'wrong' with the individual.

In progressing towards the ratification of the CRPD, there has been movement by the Disability Sector to shift the mindset of the way people think about disability from using the terms such as "illness" and "sick" to the term "people with disabilities".²⁷ The focus is now on how the physical and social environment limits what people can do²⁸ thus reflecting the human rights based approach.

Disability as defined in the CRPD

The CRPD maintains the idea that disability results from the interaction between people with disabilities (or impairments) and the barriers that hinder their participation in society on an equal basis with others. It focuses on the barrier **and not** on the person with the impairment. The CRPD provides a flexible definition of 'disability' in Article 1 where it states:

²⁶ In other cases, the SBS definition of people with disabilities was defined or recognized a person with disability as "Anyone with a condition (physical/emotional) causing great harm to one's life hence making it difficult to live life to the fullest without support from others. See *Housing and Population Census 2011*, section 7.5, at pg. 51

²⁷ The Disability Sector in the *NPPD 2011-2016* agreed to use the term "people with disabilities" at pg. 7

²⁸ See *Ibid* 27 above.

“The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all people with disabilities, and to promote respect for their inherent dignity.

*People with disabilities **include** those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”*

This definition includes people with long-term physical, mental, intellectual and sensory impairments. The use of the word ‘*include*’ in the definition “could therefore extend the application of the CRPD to all people with disabilities. Such as people with short-term disabilities or people who are perceived to be part of such groups”.²⁹ This approach leaves it open for governments to define disability in national legislation and policies, as might be necessary in specialist sectors such as employment and health.³⁰

It is the view of the Office that any definition to be adopted in Samoa should therefore reflect the *human rights based approach* where the focus is on the removal of barriers rather than the degree of the person’s impairment.

2. What is the CRPD?

The CRPD is a Human Rights Convention that recognizes the rights of people with disabilities. While they have the same rights as people without disabilities, State Parties must take additional measures to ensure the realization of those rights. As such, it also sets out the obligations of governments to promote and protect these rights in recognition of the challenges faced by people with disabilities in realising such rights.

The CRPD does not seek to create new rights but only seeks to clarify, reaffirm and expand upon the rights which have long been recognized in other human rights legal instruments.³¹ Some of these legal instruments have been ratified and adopted as law by Samoa.³² Samoa will become legally bound to the CRPD once it ratifies it and therefore all the Articles in the CRPD will become mandatory for the Government to implement.

All-encompassing principles, obligations and rights under the CRPD

The first few Articles of the CRPD as highlighted below include *principles, obligations and rights* which have an all-encompassing effect on all the other Articles in the CRPD. All the Articles of the CRPD should be read together with the following Articles:

- a) Article 3 – General principles;
- b) Article 4 – General obligations of the government;
- c) Article 5 - Equality and non-discrimination;
- d) Article 7 – Children and with disabilities;
- e) Article 8 – Awareness-raising;
- f) Article 9 – Accessibility.

To highlight this point, the Articles relating to Education (Article 24), Employment (Article 27) and Health (Article 25) must be read together with the Article on Accessibility as follows:

²⁹ The Convention of the Rights of People with Disabilities ‘*Training Guide, Professional Training Series No.19*, United Nations of the Office of the High Commission at pg. 25.

³⁰ See *Ibid* 34 below at pg 26.

³¹ Such as ICCPR, CEDAW, CRC, ICESCR, CAT, ICERD, CED.

³² See UDHR, ICCPR, CED, CEDAW and CRC.

Other Rights	Explanation
<i>Right to Education</i>	Without accessible transport to schools, accessible school buildings, and accessible information and communication, people with disabilities would not have the opportunity to exercise their right to education. ³³
<i>Rights to Health</i>	All information and communication pertaining to the provision of health care should be accessible through appropriate modes, means and formats of communication. ³⁴ Even if the buildings where health-care and social protection services are provided are themselves accessible, without accessible transportation, people with disabilities are unable to travel to the places where the services are being provided.
<i>Right to Employment</i>	People with disability cannot effectively enjoy their work and employment rights if the workplace itself is not accessible. Besides the physical accessibility of the workplace, people with disabilities need accessible transport and support services to get to their workplaces. All information pertaining to work, advertisements of jobs offers, selection processes and communication at the workplaces that is part of the work process must be accessible through appropriate mode, means and formats of communication. ³⁵
<i>Right to participate in political and public life</i>	This guarantees the right to participate in political and public life, and to take part in running public affairs. It is important that the voting procedures, facilities and materials are accessible through the appropriate modes, means and formats of communication ³⁶ and easy to understand. Furthermore, political meetings and materials used and produced by political parties or individual candidates participating in public elections are accessible.

This is one example of how these first few Articles of the CRPD of the all-encompassing effect these Articles have on the rest of the CRPD. However, the full effect will be discussed further in this report.

Implementation of obligations under the CRPD

Immediate vs Progressive

Government do not have to fully implement **all** the obligations under the CRPD upon ratification. The CRPD allows for the *gradual or progressive* implementation by governments of the social, economic and cultural rights (such as Accessibility, Education, Employment and Health) based on the available resources of governments. The concept of progressive realization recognizes that governments have different economic capacities but they are not allowed to advance insufficient resources as a reason to avoid implementing the CRPD. With respect to other rights, particularly civil and political rights such as the right to equal recognition before the law (Article 12), governments must take immediate steps towards the realization of these rights.³⁷

Private Sector

The protection and promotion of any human rights should not lie solely with government; it requires a collective effort and contribution of all levels of society. The CRPD goes further than other treaties in identifying specific areas for action by the private sector. The private sector or private entities/enterprises are mentioned in the Articles on: general obligations (Article 4 (1) (e));

³³ See Article 24 of the CRPD.

³⁴ For instance sign language, Braille, appropriate electronic formats, alternative script, and augmentative and alternative modes.

³⁵ See *Ibid* 37 below.

³⁶ See *Ibid* 37 below.

³⁷ Committee on the Rights of People with Disabilities, General Comment No.1, *Article 12: Equal Recognition before the law*, 11th Session (31 March – 11 April 2014) at pg. 7

accessibility (Article 9 (2) (b)); personal mobility (Article 20 (d)); freedom of expression (Article 21 (c)); health (Article 25 (d)); and work (Article 27 (1) (h)). The CRPD urges the private sector, directly or through their governments, to ensure that the rights of people with disabilities are promoted and protected in their line of work.³⁸

In addition to private enterprises, it is possible to identify other actors, beyond States, with responsibilities to respect the rights of people with disabilities. For example, Article 25 refers to health professionals. Several articles refer to support services and community services (for example, Article 12 in relation to support for exercising legal capacity and Article 19 on independent living). Article 24 refers to the employment of qualified teachers to promote inclusive education. So even though the legal responsibility to respect the Convention lies with the State, many other actors have a role to play. It is the view of the Office that the responsibility to implement the CRPD should not just be the responsibility of government or the private sector. It should be the responsibility of everyone.

³⁸ The Convention of the Rights of People with Disabilities ‘*Training Guide, Professional Training Series No.19*, United Nations of the Office of the High Commission at pg. 33.

PART IV: ANALYSIS

As noted previously, the Office carried out extensive consultations. The views and perspectives of everyone involved in the consultations, Survey and focus groups will be highlighted throughout this report. However, some opinions do not necessarily reflect the views of the Office, rather, the quotations and case studies are meant to provide a human perspective within the report.

Over the course of its research and consultations, the Office encountered the following issues that it would like to bring to the attention of Parliament:

Lack of Disaggregated Data Collected

One of the biggest challenges discovered from the outset was the lack of meaningful disaggregated data on the population of people with disabilities. It became apparent through the consultations with NGOs that each NGO has its own data pertaining to people with disabilities who are their clients.³⁹ The Office was unable to gain access to this data due to confidentiality reasons.

There were also Government agencies with no available data on people with disabilities.⁴⁰ The Office acknowledges the progress made by Samoa Bureau of Statistics (“SBS”) and MWCSD in carrying out and putting together the Samoa Disability Prevalence Report (“SDPR”) 2015. However, the SDPR is incomplete as the statistics are unweighted.⁴¹ The Office has used these statistics as they are the only well disaggregated data that can give some indication on the numbers related population of people with disabilities. Therefore, it is important to keep this in mind when reading references of the SDPR in this report.

This report raises the need for proper and effective coordination across the Disability Sector to coordinate data on the disability population in one database to be monitored by at least one stakeholder.⁴² This database can be used as the same reference point for all interested parties to prevent the duplication of data collection as well as ensure the consistency and accuracy of the information recorded and used.

Moreover, Samoa must ensure meaningful disaggregated data on disability is included in all reporting to ensure achievement and monitoring of policies and programs in the implementation of the CRPD. Further, Government will also comply with the CRPD.⁴³ It is important to note that the MWCSD with the assistance of Motivation Australia and the Department of Foreign Affairs and Trade (“DFAT”) are currently implementing a monitoring and evaluation framework which will seek to co-ordinate the data collected relating to disability by relevant stakeholders.

Lack of direct Government financial support

It appears that the Government has had minimal direct financial involvement in providing support for people with disabilities and their families/carers. This may be attributed to the role of *Fa’asamoa* and the family unit in caring for people with disabilities with some assistance of the NGOs. The provision of services for people with disabilities have been primarily provided by NGOs⁴⁴ over the years with the financial assistance of international donors and minimum financial support by the Government.

³⁹This was a main issue that was raised during consultations with NGOs as well as Government Ministries. Some NGOs blame others for not sharing their data and some Government Ministries were blaming NGOs for not sharing resources with one another.

⁴⁰ Such as NUS, OEC, MWTI, MNRE, DMO, NHS, MOH, MoP, MCIL, PSC.

⁴¹ See *Samoa Disability Prevalence Report 2015*, at pg. 13.

⁴² This is not the only report that has raised this issue. Other reports include the *NPDD 2016-2020* at pg. 4-5.

⁴³ See Article 31 of the CRPD which requires the State to collect appropriate information including statistical and research data and comply with legally established safeguards to protect the privacy of a person with a disability.

⁴⁴ For instance, SENESE, Loto Taumafai, Samoa Blind People Association, Aoga Fiamalamalama, Goshen Trust, SVSG, Special Olympics, Samoa Spinal Network, NOLA.

They have all contributed in the provision of various forms of services and assistance to people with disabilities so that they may receive some support to enjoy an adequate standard of living.

Currently, the coordination of Disability Programs (including activities and services) is largely funded by international donors particularly by the Australian Government through the *Samoa Disability Program* (“SDP”) 2013-2017. With the ratification of the CRPD, it is hoped the Government of Samoa will co-fund the *SDP 2013-2017* and eventually assume responsibility towards full funding of the *SDP 2013-2017*.

Better co-ordination between NGOs

While the Disability Unit within the MWCSD as the focal point administers the SDP, there needs to be a specific co-ordinating office which coordinates the key priorities of each local NGO so that there is no duplication of provision of services within the NGO sector. This Office does not seek to control NGOs but it is only for the purposes of co-ordinating the work of NGOs to set key priorities for the NGOs so that each NGO knows its respective role in providing services for people with disabilities. To that end, the Office agrees with the *NPPD 2016-2020* where it states that in relation to the provision of mobility devices in Samoa:

“At the operational level, there are perceived risks related to communication, equitable coverage and resource distribution (duplication), which warrant the need for better coordination and management”

Lack of family support

Throughout this report, the critical role of the family is emphasized as the way in which families care for their relatives with disabilities affects (to some extent) the realisation of the rights of people with disabilities. Given the significance of the families’ role, it is the view of the Office that attention must be given to the education of families in respecting, protecting and promoting of the rights of people with disabilities. Having the strong support of the family unit will assist Samoa in the implementation and fulfilment of its obligations under the CRPD. It would be counter-productive for the government to provide access to employment, education and other services when families themselves place no value on the exercising their relatives’ rights.

“We encourage the parents to attend our activities with their children so that they can learn the activities and be able to do it with their children at home. We believe that doing these activities with their children with disabilities will not only keep them active but helps them to learn about their children’s behaviours and learn to understand and deal with it. However in many cases the parents are not always willing to cooperate...they say they don’t have the time because of other obligations and commitments...having the support of their families particularly their parents is vital to the success of our program”

“Even when there are services available our parents sometimes only bring their children if they get something out of it like money or food so it’s really hard to make it work without their support”

Recommendation:

- 1) The Government should develop an action plan in order to co-fund the SDP 2013-2017 with the aim to completely fund the SDP 2013-2017 upon its completion.**

1. Equality and Non-Discrimination

Many people may use the terms **equality** and **non-discrimination** without fully understanding their meaning. In human rights law, non-discrimination and equality are two sides of the same coin. By combating discrimination, we hope to combat the underlying factors in society that lead to inequality. And if we deal with the factors leading to inequality, we hope to prevent discrimination.⁴⁵

Equality means we are all the same and we all have equal worth simply by *being human* regardless of our differences including disability. This concept requires not only individuals, but also societies in which they live, to accommodate human differences. There are three types of equality in human rights: (i) *formal equality*, (ii) *equality of opportunity* and (iii) *substantive equality*.

Type of Equality	Definition/Explanation	Example
Formal equality	Are laws and policies that are either discriminatory towards people with disabilities (and which need to be amended to remove such discrimination) or laws and policies which ensures that people with disabilities are treated the same as everyone else.	Constitution of the Independent State of Samoa 1960 (Article 15) Labour and Employment Act 2013 (s. 20) Education Act 2009 (s.19)
Equality of opportunity	While formal equality is an important step in ensuring people with disabilities are fully protected in Samoa, it will not completely remove all the barriers that people with disabilities face every day. Requires specific actions by individuals and governments which complement formal equality measures to ensure that people with disabilities can enjoy the same opportunities as everyone else.	These include (but are not limited to) providing access to transport and buildings and combating stereotypes and attitudes that exist in Samoa which can lead to discrimination against people with disabilities.
Substantive equality (or de-facto equality)	When special measures are put in place to ensure that there is actual equality for people with disabilities. This not only recognises that people with disabilities are disadvantaged, but goes further by proactively trying to correct this disadvantage via special programs and policies that are specifically targeted to people with disabilities.	A recent example of a substantive equality undertaken by the Government of Samoa was the implementation of a mandatory quota for women to be represented in Parliament.

Discrimination is treating someone differently or unfairly based on one or more personal attributes (e.g gender, religion, sexual orientation, disability etc). In the context of disability, non-discrimination *prohibits* discrimination against anyone on the basis of their disability. It is a fundamental principle of the CRPD⁴⁶ and involves not only prohibiting acts of discrimination but also taking active steps to

⁴⁵ The Convention of the Rights of People with Disabilities ‘*Training Guide, Professional Training Series No.19*, United Nations of the Office of the High Commission at pg. 82.

⁴⁶ See Article 3 of the CRPD.

protect people with disabilities from acts of discrimination in the future. A person with a disability may experience discrimination in two different yet, equally destructive, forms:

Type of Discrimination	Definition/Explanation	Example
<i>Direct Discrimination</i>	It is when a person with a disability is treated less favourably than another person without a disability <i>because of the person's disability</i> . This is the most obvious form of discrimination	A person with a disability is not given a job because it is assumed that their disability will prevent them from carrying out the duties in the job description.
<i>Indirect Discrimination</i>	This occurs when there is an unreasonable practice, policy or rule that is applied to everybody equally but which results in an unfair, disproportionate effect on people with disabilities.	The only way to enter a public building is by stairs. This unfairly discriminates against a person who uses a wheelchair as they may find it difficult to enter the building.

1.1 Equality and Non-Discrimination in the CRPD

Article 5 provides that everyone is equal before and under the law. Everyone is entitled to the equal protection and benefit of the law without discrimination. Significantly, the principles of non-discrimination, equality between men and women, equality of opportunity and the respect for difference and acceptance of people with disabilities are all included as guiding principles for interpretation of all the specific Articles in the CRPD. Article 4 provides a general obligation by governments to ensure that there should be no laws that discriminate against people with disabilities to give effect to Article 5. The CRPD requires the State to:

- (a) prohibit all discrimination on the basis of disability as well as guarantee effective legal protection against all types of discrimination; and
- (b) take proactive steps in promoting equality and eliminating discrimination by ensuring that all ‘*reasonable accommodation*’ is provided to people with disabilities.

Reasonable Accommodation:

Reasonable accommodation requires government to ensure that duty bearers (e.g employers, educators, providers of goods and services, public authorities etc) adjust their policies, practices, facilities and premises to remove the barriers, which combined with a person’s impairment, results in disability.⁴⁷ Duty bearers do not need to remove these barriers if it means that it would create a ‘*disproportionate or undue burden*’ on the duty bearer. This is, the cost (financial or otherwise) of the removal of the barrier should not impose an undue burden on the person having to remove the barrier. For instance, when a person with a severe sight impairment is not considered for a job because the employer’s computer system could not be adjusted to accommodate the person’s sight impairment. The employer could argue that to change the computer system would impose a disproportionate or undue burden on the employer.⁴⁸

⁴⁷ Article 2 of the CRPD defines “reasonable accommodation” as necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to people with a disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

⁴⁸ See Marie-Louise Jungelin v. Sweden, CRPD Committee Communication No. 5/2011, 14 November 2014. The Committee in that case said that when assessing ‘reasonableness and proportionality of accommodation, States ‘enjoy a certain margin of appreciation’, at pg 10.5.

1.2 Current Legal Framework

Article 15(1) of the Constitution of the Independent of Samoa 1960 (“Constitution”) provides equal protection for everyone before the law which is similar to Article 5 (1) of the CRPD that “*All people are equal before the law and entitled to equal protection under the law.*” Article 15(1) of the Constitution has been interpreted by the Supreme Court of Samoa⁴⁹ as having the same intent as that of Article 14 of the European Convention on Human Rights which provides that the enjoyment of the rights to freedom set out in the convention “*shall be secured without discrimination on any ground.*”

In addition to the Constitution, the only legislation which specifically provides for anti-discrimination is the *LER Act*⁵⁰ which protects people with disabilities from discrimination in employment.⁵¹ It is also worth noting that the provisions of the *Education Act*⁵² also seek to prevent discrimination by including people with disabilities to be educated in the general education system.

1.3 Current Situation

Although Samoa recognises discrimination against people with disabilities, the Office discovered many examples of direct and indirect discrimination during consultation and home visits. Some of the common examples are:

- a) a lack of specialist transportation that can assist people with disabilities (such as those using mobility aids) to get from place to place. Further, it is difficult for them to use transport as the steps are either too high or there are no ramps to allow access.⁵³ This is most common in Savaii where many people do not have access to a private vehicle.

“We used to live in Apia so she was able to attend the school because the school would pick her up in their van but now that we’ve moved here the school van doesn’t cover this far of the country and of course we can’t get her into the bus with her wheelchair and catching a taxi is just too expensive, so she stays home”

- b) a barrier for children with intellectual and psychosocial disabilities in rural areas to attend mainstream schools because teachers and principals say that they did not have the experience or capacity to cater for these children. In other cases, the children with an intellectual impairment are being kept at home by their parents for fear they would be teased.

“I’m 20 years old and I have cerebral palsy impairment, I attended school but stopped at year 7 ...my parents didn’t think I was learning anything and plus the teachers prioritise ones without disability so no point...”

⁴⁹ See *Aiono Sia v Maiava Visekota Peteru* [1998] WSSC 31.

⁵⁰ Section 20 (2) of the *LER Act* states a person must not discriminate, directly or indirectly, against an employee or an applicant for employment in any employment policies, procedures or practices on 1 or more arbitrary grounds, including ethnicity, race, colour, sex, gender, religion, political opinion, national extraction, sexual orientation, social origin, marital status, pregnancy, family responsibilities, real or perceived HIV status and disability.

⁵¹ See section 6.2 of this report for a full discussion of this section.

⁵² See section 19 of the *Education Act*.

⁵³ SVSG notes that SVSG, with the support of its international partners, have an ambulance which was donated in early 2016 from SVSG Queensland, and an accessible van for people with disability donated by Altus Trust Resources NZ. The MDS has two wheelchair-accessible vans which are used to transport people with mobility impairments to the TTM Hospital in Motootua.

“My son used to go to school but stopped at year 5, I stopped him from going to school not because I worry he might have a fit and no one is there to help him but because he can get very aggressive (behavioural problems) when kids tease him...he throws rocks at them or slap the kids when he’s angry”

- c) a serious issue of stigma attaching to people with disabilities and generating discrimination as a result of negative attitudes of people without disabilities in the community. In fact, an overwhelming 87% of the surveyed participants who identified as having a disability, experienced discrimination as a result of their disability in the past 12 months.⁵⁴

Further, the Government is in the process of completing the LCR of all of Samoa’s legislations to harmonize them with the rights and obligations under the CRPD.⁵⁵ At the time of drafting this report, this Office understands that the LCR is still in draft form and is yet to be finalized. The Government should be commended for its work as it is no easy task due to the unique nature of the CRPD. However, as part of the LCR, the Government will need to consider how it wants to protect people with disabilities from discrimination and it may consider introducing:

- a) a Human Rights Act that seeks to codify all human rights into one single document. This can either be in the form of amending the Constitution to clarify and/or extend what is currently in the Constitution, or can be a separate Act of Parliament; or
- b) an over-arching Anti-Discrimination Act which covers all the grounds of discrimination including disability in the areas of employment, education, social status and disability; or
- c) a specialist People with Disability Bill which includes anti-discrimination protection specifically for people with disabilities.

Women with Disabilities

Discrimination against women is also a concern that was observed during home visits. Women with disabilities are more likely to experience discrimination than men with disabilities.⁵⁶ Article 6 of the CRPD explicitly recognizes that women with disabilities face and/or experience multiple discrimination for both being a woman and for having a disability. They often find it more difficult than men with disabilities to find employment, attend school, participate in political life, and marry or have a family. One of the main focus of Article 6 is to prevent violence, exploitation and abuse of women with disabilities. This Article can be read in conjunction with:

- a) Article 3 which provides that ‘equality between men and women’ means that all the provisions contained within the CRPD (including Article 6) need to be interpreted and applied in light of the concept of gender equality; and
- b) Article 16 which requires governments to take measures to protect people with disabilities from violence, exploitation and abuse. This includes helping people with disabilities, as well as their carers and family, by providing information and education on how to recognise and report cases of abuse.

From the home visits two issues were identified. Firstly, there was a lack of reporting of abuse of women with disabilities to the police by victims and families. There are no clear avenues of reporting for women with disabilities when they are subjected to abuse and exploitation. Secondly, it is unclear whether or not the police are specifically trained and equipped to handle complaints of abuse and

⁵⁴ It is important to note that in the Survey, 20 respondents that said they did not have disability also answered that they were discriminated because of disability.

⁵⁵ OAG consultation, 14 April 2016 on file at the Office of the Ombudsman..

⁵⁶ See (2013) Shur, Kruse and Blanke, “ *People with Disabilities – Sidelined or Mainstreamed?*”, Cambridge University Press, P 157 and BIWAKO Millennium Framework for Action in 2003, para 19, at pg. 7.

sexual exploitation of women with disabilities.⁵⁷ Through consultations with SVSG,⁵⁸ some of the women with disabilities seek SVSG's assistance in filing a report with the Ministry of Police ("MOP") and that SVSG also provides counselling and accommodation for the safety of the female with disabilities.

The Government needs to have clear guidelines for reporting abuse and exploitation of females with disabilities. These guidelines need to be gender, age and disability sensitive. Furthermore, they must ensure that women with disabilities, their careers/families, as well as the service providers and health care professionals are aware of the reporting process for people with disabilities who are suspected to be victims of such abuse.

Case Study: Abuse of Women with Disabilities

During the course of its inquiry, the Office came across two cases of suspected sexual abuse of women with psychosocial disabilities. In one case, one woman had given birth to two children, one of whom may have been conceived while the woman was below the age of 16. The woman currently lives with her aunty, uncle and two children. Her family said that they try to monitor her whereabouts and she is not allowed to walk too far from the house.

The Office was told by a disability service provider that the woman had been questioned by the Police about who the father was of the two children. The service provider said that it appeared that the woman has been told what to say, as she kept telling Police officers different names of different men within her village.

This case study highlights three issues. The first is the lack of independence the woman enjoys because her family does not allow the woman to walk too far from the house because they are worried that she will be taken advantage of if she is not constantly monitored. Secondly, the woman has been taken advantage of because of her disability and the fact that she is a woman. Thirdly, there is little that the Police can do in such situations as there does not appear to be clear guidelines for reporting abuse of women with disabilities.

Recommendations:

- 2) **OAG, MWCSO and SLRC should complete the LCR and ensure that it fully harmonises all of Samoa's laws with the CRPD.**
- 3) **The MOP should develop clear guidelines for reporting abuse and sexual exploitation of women with disabilities. These guidelines should be gender, age and disability sensitive.**

2. Accessibility and Mobility

Accessibility is important for people with disabilities to live independently and participate fully and equally in society.⁵⁹ This is because a lack of access can prevent people with disabilities from enjoying all of their human rights. Accessibility focuses on overcoming the barriers that exist in society that prevent people with disabilities from enjoying other rights.

The right to personal **mobility** ensures that people with disabilities are provided or have access to mobility aids/devices that they require to help them gain independence as well as the ability to move and access society, including to participate in mainstream activities such as schooling, sporting and cultural activities. Such things can include electronic readers for people with vision impairments,

⁵⁷ The Office contacted MOP for clarification on this issue but did not receive any feedback in time for the preparation of this report.

⁵⁸ SVSG consultation, 4 February 2016 on file at the Office of the Ombudsman.

⁵⁹ Committee on the Rights of People with Disabilities, General Comment No.2, *Article 9: Accessibility* at pg.4.

hearing devices for people with hearing impairments, as well as walking aids, wheelchairs and prostheses and orthoses for people with physical impairments.⁶⁰

2.1 Accessibility and Mobility in the CRPD

The CRPD is the first legally binding instrument that clearly articulates the concept of accessibility for people with disabilities. The provision of accessibility allows for the effective enjoyment of other rights of people with disabilities under by the CRPD such as the right to education, health and employment as discussed in section 2.1 of Part III of this report.

Article 9 requires government to ensure accessibility for people with disabilities so they can “*live independently and participate fully in all aspects of life*” which includes people with disabilities enjoying the same level of access to the:

- a) physical environment: includes buildings, roads, indoor and outdoor facilities including schools, hospitals, workplace etc);
- b) transportation: includes such as buses, airplanes, taxis, and ferries; and
- c) information and communication: includes any information and communication device and its content such as radio, television, phones, satellites, computers.

According to the CRPD Committee as long as goods, products and services are open or provided to the public, they must be accessible to all, regardless of whether they are **owned and/or provided by a public authority or a private enterprise**.⁶¹ In order to achieve access to all these things, the CRPD provides that government would need to first identify the barriers to equal access so that they can be removed over time.⁶² In doing this, government must also keep in mind the provision of *reasonable accommodation* as discussed in section 1.1 of Part IV of this report. As previously discussed in this report, the CRPD allows for gradual implementation of certain rights and Accessibility is one of those rights.⁶³

Article 20 and the Standard Rules for the Equalization for People with Disabilities specifically set out the obligation of government to ensure that people with disabilities have access to mobility aides/devices. This is a new obligation that is imposed on State Parties in recognition of the importance of independent mobility for people with disabilities to study, work, and participate in family and community life. However, services relating to mobility devices do not simply involve giving a person with disability a wheelchair or walking aid. It also involves referrals, assessments, product preparations, fitting and adjustments, user training and follow up. As such the CRPD requires government to take effective measures to ensure personal mobility with the greatest possible independence for people with disabilities by:

- a) Facilitating the personal mobility of people with disabilities in the manner and at the time of their choice, and at an affordable cost;
- b) Facilitating access by people with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
- c) Providing training in mobility skills to people with disabilities and to specialist staff working with people with disabilities;
- d) Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for people with disabilities and include people with disabilities in the decisions about their treatments.

⁶⁰ See Article 4(g) (h) of the CRPD.

⁶¹ Committee on the Rights of People with Disabilities, General Comment No.2, *Article 9: Accessibility* at pg.4.

⁶² See Article 9 of the CRPD.

⁶³ See *Ibid* 61 above.

2.2 Current Legal and Policy Framework

Buildings

The *Ministry of Works Act 2002* (“MoW Act”) regulates the construction of buildings and other structures through the development of a Building Regulation to prescribe the requirements⁶⁴ for buildings. However, there is no Building Regulation⁶⁵ but the Ministry of Works, Transport and Infrastructure (“MWTI”) is currently drafting one. The draft Building Regulation is intended to ensure that the technical and regulatory requirements of public buildings recognize, respect and protect the rights of people with disabilities.⁶⁶ The draft Regulations may include the National Building Code (“NBC”) which MWTI⁶⁷ adopted in 2002 as Samoa’s first NBC.⁶⁸ The NBC did not provide sufficient provisions relating to the access (into and within buildings and appropriate sanitary facilities) for all people with disabilities. The NBC is currently under revision⁶⁹ and intends to specify requirements (e.g sensory, outdoor and indoor accessibility; automated access which includes lifts, escalators, moving walkways, automated ramps; as well as handrails and ramps) for *public and residential* buildings to ensure accessibility for people with disabilities.

In addition to the efforts of MWTI, the Planning and Urban Management Agency (“PUMA”) under the Ministry of Natural Resources and Environment (“MNRE”) developed the following related policies:

- a) the *PUMA Disability Access Guideline 2008*. It provides the requirements for the provision of access to public facilities⁷⁰ which includes car parking, kerb ramps, doors, access to buildings, ramps, street furniture, pathways, signage, stairs, lifts, toilets, and showers;
- b) the *Planning and Development Guideline for Housing* dated 20 October 2005/2006 for planning and design of new residential development. New developments for private dwellings are required to have ramps/ pathways, door and door handles, interior walkways;⁷¹
- c) the *Samoa National Urban Policy October 2013*, established a strategic framework for shaping the physical form of the Apia urban area and provide national guidance for future investments in infrastructure and services. The overall mission goal is “Sustainable, Inclusive and Resilient City”. However there is lack of reference of an Inclusive City for people with disability.

Further, the *NPPD 2016-2020* focuses on the enforcement of buildings codes, as well as implementing and monitoring national construction standards to provide access for people with disabilities.⁷²

⁶⁴ The requirements include access to and the provision of essential services to buildings and any other matter that might affect the buildings, its occupants and the public.

⁶⁵ The *MoW Act* provides for the development of a Building Regulation. However, S. 27 adopts other regulations: Board of Health (Building, Drainage and Privies) Regulations No.6 1923, Board of Health (Building, Drainage and Sanitation_ Regulations No.8 1929, Board of Health (Concrete Buildings) Regulations No.116 1947 (insofar as these Regulations relate to the erection of buildings).

⁶⁶ Latest draft Building Regulations is dated April 2016. Builders, engineers and landowners will be required to refer to both Building Regulations and NBC documents for any development project.

⁶⁷ MWTI in collaboration with other relevant stakeholders put together the NBC.

⁶⁸ See Part V of the *MoW Act*.

⁶⁹ The NBC is still in draft form. Latest draft dated April 2016.

⁷⁰ Including hospitals, schools, cinemas, commercial and institutional buildings.

⁷¹ See para 3.10 pg 34 of the *Planning and Development Guideline for Housing*.

⁷² See Outcome 6 of the *NPPD 2016-2020* for the implementation and monitoring provisions within national frameworks that provides for disability inclusive accessibility.

Case Study: Herbert- Reasonable Accommodation

Herbert Bell is 29 years of age with a visual impairment. He has been blind since birth. He is a well-known radio presenter for Samoa FM, where he has worked full time for the past 6 years. According to Herbert, finding a job was never easy and that people are not always willing to hire people such as him because of his disability. However, his boss at Samoa FM not only believed in his talents and looked past his disability when they hired him, they were also very accommodating by making sure that he is familiar with his workplace surroundings.

Samoa FM didn't need to make renovations to accommodate for Herbert but rather walked Herbert through the workplace to familiarise him with where things are. His employers and staff would always notify Herbert if anything changes in the set-up of the room such as tables, chairs etc. This has allowed him to feel independent where he does not rely on anyone to guide him. He enjoys his job and his working environment where he feels comfortable and part of the team like everyone else.

Roads and Footpaths

There is a lack of laws and policies in place to ensure that the roads are safe and accessible for people with disabilities. The *Land Transport Authority Act 2007* has no specific provisions to guarantee that the roads constructed are also accessible by people with disabilities. Further, the Transport Sector developed Samoa's first *Transport Sector Plan 2014-2019* ("TSP") with a vision to ensure "Sustainable, safe, secure and environmentally responsible transport network that supports Samoa's economic and social development and contributes to improving the quality of life for all Samoans".⁷³ The TSP contains very little discussion about ensuring Samoa's transport system is accessible by people with disabilities. It identified that Samoa's road network does not cater for pedestrians. There is, therefore, a need to provide better pedestrian facilities and safer footpath for people with mobility difficulties,⁷⁴ Footpaths that will, in fact, benefit all pedestrians.

On the other hand, PUMA in July 2006 developed a Parking Policy and Standards which ensured parking spaces to be allocated for people with disabilities.⁷⁵ The MWTI may also make provision for car parking⁷⁶ as per its Building Regulations. The *NPPD 2016-2020* noted that there needs to be improvement of accessibility by people with disabilities to roads in communities via mainstreaming accessibility in village plans, and develop system for issuing IDs for disability parking.⁷⁷

Transportation

The *Land Transport Authority Act 2007* provides for the LTA to "establish and enforce standards for vehicle registration⁷⁸ and develop and implement traffic management strategies and practices consistent with the needs of roads users and the objectives of road safety".⁷⁹ There appears to be no standards for public vehicles to ensure accessibility by people with disabilities, for instance low floor or ramps.⁸⁰

⁷³ See *Transport Sector Plan 2014-2019* "A Transport Network to Future Prosperity" Vol I, at pg. iii.

⁷⁴ See *Ibid* 76 at pg. 17.

⁷⁵ See PUMA *Parking and Policy and Standards* at para 4.3, pg. 13-14

⁷⁶ See *Ministry of Work Act 2002* at s.28 (2.e.i)

⁷⁷ See Outcome 6 of the National Policy on People with Disabilities at pg. 17.

⁷⁸ See *Land Transport Act 2007* at s. 5.1 (d) (ii)

⁷⁹ See *Ibid* 81 at s. 5.1 (d) (vi)

⁸⁰ The *NPPD 2016-2020* states that there is a need to review provisions for accessibility within land/sea/aviation systems. See Outcome 6, at pg.17.

Information and Communication

The *Telecommunication Act 2005* provides for the legislative framework for telecommunication. Two of its objectives is to promote universal access to telecommunications services at affordable prices, and to promote the introduction of advanced and innovative information and communications technologies to meet the needs of the people of Samoa.⁸¹ Further to the Act, Ministry of Communication, Information and Technology (“MCIT”) developed a *National Information and Communication Technology Policy and Strategic Plan 2012-2017* which reflects the Government’s vision of “Information and Communication Technologies (ICT) for ALL”. It describes the Government’s ambition to foster greater utilization of ICT by all Samoans, in all communities and in all aspects of their life. In measuring this goal, there appears to be no clear indication of measures in the Policy to ensure people with disabilities as users of ICT have access to such services.

2.3 Current Situation

Buildings

Despite the development of laws and policies, there is minimal access to public buildings by people with disabilities. Some recently built buildings have incorporated some form of access such as ramps, elevators, rails. For an example, the Court House has ramps, elevators, rails; the TATTE Building has ramps and elevators; the MWCSD head-quarters has ramps and rails; and the Government Building has ramps and elevators. In other cases, some churches and schools have built ramps.

Although ramps already exist some are inappropriately built where they are too steep for a wheelchair user to self-propel and therefore a person may be reliant upon assistance for access. In other cases, it was evident from the home visits that generally there is poor accessibility for people with physical impairments into and around their own homes as many homes are either built on concrete slab or use stone foundation without stairs or ramps. Further, access to many houses is hindered by the rough terrain (paema’a, volcanic rocks etc) surrounding their homes. As will be highlighted later in the report, the lack of accessibility to building can have a direct impact on other rights, such as the rights to education and employment.

Roads and Footpaths

The lack of laws and policies in places to ensure accessibility to roads for people with disabilities reflects the current poor accessibility of Samoa’s roads. An obvious example is the lack of footpaths (not only on public roads but also residential and commercial areas) to be used by people with disabilities, particularly wheelchair users. This may have been unintentional and may be attributed to a lack of awareness and resources, as well as the fact that people with disabilities are a marginalized population. Recently, there have been developments leading to the improvement of the designs of national roads in the town areas to include the construction of walkways/sidewalks and traffic lights that are accessible for people with vision impairments.

⁸¹ See s.3 (b) and (d) of the *Telecommunications Act 2005*.

Transportation

“I have a visual impairment. Public transportation is a challenge for me especially the bus. My office has no vehicle so I catch the bus to go to all the schools (rural and urban) which enrol students with visual impairments to collect their homework from their teachers to translate into braille for the students and print for the teachers. Due to no reliable bus schedules, I would spend the night with families in the rural areas and catch the first bus in the morning to town. Once I finish translating I would have to catch the bus again to drop off their homework to the teachers.”

“My son has cerebral palsy and was given a wheelchair by Loto Taumafai to assist with moving him around but there is no point because when we go to places particularly taking him for his check up at the hospital..my husband carries him because we can't get his wheelchair onto the bus and we do not have our own vehicle”

There is poor access to transportation for people with disabilities with respect to buses, taxis, ferries and aeroplanes. According to MWTI people with disabilities are provided with wheelchairs to the aeroplanes and are given priority for boarding and also are given care on arrival at their destinations. However, the wheelchair can only take the person with disability to the stairs and they are then carried to their seats. One of the ferries has an elevator but it appears to be out of service most of the time. There are no policies or standards requiring accessible public transportation (e.g buses and taxis without any low floor or ramps). There are no public transport providers with accessible vehicles.

Information and Communication

The consultations showed that there is minimal assistance by the Government to allow people with disabilities to have access to information or communication.⁸² As attractive as MCIT's policies appears it however lacks implementation.⁸³ According to MCIT this was due to (i) lack of resources and (ii) changes in MCIT's priorities over the last couple of years which prevented the implementation of its Policy for the inclusion of people with disabilities.

The Office of the Regulator assists people with disabilities who are educated at SENESE through the provision of free spectrum license in order for the students with hearing and vision impairments to use their hearing devices and braille. Some examples of assistance by NGO service providers currently available for people with disabilities to access information and communication include:

- a) SENESE Inclusive Education Services assists children with disabilities from the years 0 to 18 by making available Teacher Aides to assist the students to communicate and understand the teacher and school work through sign language and braille;
- b) Samoa Blind People Association focuses on students below the age of 18⁸⁴ who are fully blind by helping the students learn how to read and write in braille. Staff also transcribe work from teachers into braille then translate the student's work from Braille to English/Samoan. Trainings in Braille are carried out at schools and at other times at family homes. However, funding only allows for students below 18 not for adult population;

⁸² An "Accessibility Guide" is in the SIMDES project work plan for 2016-17. There will be consultation with the Disability Task Force stakeholders regarding the content.

⁸³ The *NPPD 2016-2020* seeks to enhance accessibility to information, review and implement relevant ICT policies, mainstream disability needs in communications strategies of all ministries and all sectors. See *NPPD 2016-2020* at pg. 16-17, 32-33.

⁸⁴ Samoa Blind People Association consultation, 5 February 2016 on file at the Office of the Ombudsman..

- c) Aoga Fiamalamalama focuses on young adults and children with intellectual disability where they provide sign language assistance; and
- d) Loto Taumafai provides an Early Intervention/ Community Based Rehabilitation Program, Primary and Secondary School for children with a range of disabilities, Vocational Training and Silent World Theatre for the Hearing Impaired.

CASE STUDY: Lack of accessibility to information

X has a visual impairment. He works for the Samoa Blind People Association. He helps students with visual impairments by translating instructions from their teachers to braille and the student's homework to print. He goes to all the schools with students with visual impairments and collect instructions or homework's from students and teachers for translation. When he is done with the translation, he returns them to the teachers and students.

Furthermore, the Disaster Management Office recently developed a *People with Disability in Disaster Risk Management Policy* in June 2015 with a focus on the integration of disability inclusive programs and procedures across all phases of disaster risk reduction and management in Samoa.⁸⁵

In addition to government obligations, private sector service providers to the general public, including through the internet, are urged to provide information and services in accessible and useable formats for people with disabilities. The mass media, including providers of information through the internet are encouraged to make their services accessible to people with disabilities.⁸⁶

Mobility

Mobility device services in Samoa have been largely provided by NGOs (including church groups), international charitable organizations and donor partners (such as the Australian Government). For instance, Loto Taumafai, SVSG and SENESE (with the help of overseas providers) offer mobility and/or assistive device services to their clients in the form of wheelchairs or hearing assessments and devices. Additionally, they provide training and fitting services to their clients.

However, with the assistance by the Government of Australia, there has been a further development of mobility services since the establishment of the SDP which runs for a period of four years from 2013-2017.⁸⁷ Mobility Device Services ("MDS") is located behind the Tupua Tamasese Meaole Hospital at Moto'otua in new facilities which were built by the assistance of the World Bank, New Zealand ("NZ") Aid Programme, and Australian Aid. The service provides wheelchairs and walking aids that are appropriate for Samoan conditions, with parts that can be replaced and fitted locally.⁸⁸ In 2016 the MDS will add services for people who require Prosthetic and Orthotic devices. All MDS services are available for children and adults. The services are delivered by trained NHS personnel.

Introducing new ideas and ways of working can be challenging, but the NHS has made a strong commitment to providing these services. Inevitably it will take time to raise awareness in Samoa about the benefits of appropriate mobility devices; service providers have to work with people with disabilities and their families to identify the best option in each situation, incorporating their views in the decision making process. During consultation before the project, the lack of accessible transportation was identified as a barrier for people with disabilities accessing services in Samoa. To address this issue, the MDS has a wheelchair accessible van that is available to transport clients to and from the MDS. The MDS team make visits to communities to follow up clients who already have a mobility device to ensure the fit and function is appropriate. The MDS team also regularly visit Savai'i for assessments and follow ups.

⁸⁵ DMO consultation, 11 April 2016 on file at the Office of the Ombudsman.

⁸⁶ See Article 9 of the CRPD.

⁸⁷ NOLA SDP Annual Report 2014-2015 at pg. 4.

⁸⁸ MDS consultation, 5 April 2016 on file at the Office of the Ombudsman..

Currently, services for hearing impairments are provided by SENESE mainly for its clients and may also include members of the public. However not everyone has access to these services as they may not be aware of its existence. At the time of writing of this report, the Office could not confirm whether NHS provides any form of services for people with hearing impairments. From consultations with DFAT, they identified that they are currently scoping for an appropriate institution to, with its initial support, set up a national service for people with hearing impairments. The Office supports this initiative and the Government should use this opportunity to develop this much needed services in Samoa.

“One of the challenges we face in the Land and Titles Court is trying to relay information during court proceedings to parties because most of them are elderly and have very poor hearing”

Recommendations:

- 4) Government should consider the following to ensure accessibility for people with disabilities:**
 - a) adopt an action plan that identify existing barriers to accessibility;**
 - b) ensure such action plans are strictly implemented;**
 - c) set time frames with specific deadlines;**
 - d) provide the human and material resources necessary to remove these barriers;**
 - e) strengthen their monitoring and regulatory framework to ensure accessibility;**
 - f) provide CRPD training and capacity building for staff that are responsible for the monitoring of these standards.**
- 5) The NHS and MOH, in collaboration with NOLA, should carry out awareness activities to ensure that people with physical disabilities and families/careers are aware of the benefits of the mobility devices and the services that are available at MDS.**

3. Awareness-raising

“Why are we bothering with the sick people when there is not many of them, how about the rest of the public and us who aren’t sick”

89% of the participants in the Survey claimed to understand the term “people with disability”. Of this number, 90% of them expressed to feel love and willingness to assist people with disabilities when they see them and 65% claimed that within the last six months they have seen at least one person with disability expressing an opinion in the media.⁸⁹ Awareness raising is an implementation measure to educate people as education is vital to understanding what disability is, their rights and obligations of the Government under the CRPD.⁹⁰

⁸⁹ The Survey attached as Annex B.

⁹⁰ The Convention of the Rights of People with Disabilities ‘Training Guide, Professional Training Series No.19, United Nations of the Office of the High Commission at pg. 73.

3.1 Awareness-raising in the CRPD

Article 8 places a high value on awareness-raising and outlines certain obligations government has to meet in order to guarantee full public awareness with regards to the rights and the needs of people with disabilities. The CRPD urges government to *immediately* adopt effective and appropriate measures to:⁹¹

- a) raise awareness throughout society, including at the family level, regarding people with disabilities and to foster respect for the rights and dignity of people with disabilities;
- b) combat stereotypes, prejudices and harmful practices relating to people with disabilities, including those based on sex age, in all areas; and
- c) combat awareness of the capabilities and contributions of people with disabilities.

3.2 Current Policy Framework

The *NPPD 2016-2020* warrants a collective approach and collaboration between the Government and civil society towards awareness-raising.⁹² NOLA, the lead organisation on disability in Samoa, is responsible for implementing awareness-raising activities and outreach programs within the community, including in schools.

3.3 Current Situation

It is important to acknowledge that Samoa has made improvements in some aspects of this obligation. Notable progress has been made since the establishment of the *SDP 2013-2017* in 2013.⁹³ One of the key outcomes of the *SDP* is to ensure that deeper community awareness of and support for the rights of all people with disability and their increased social inclusion are achieved.⁹⁴

There has been much work to ensure that this outcome is achieved. These efforts include:

- a) training of the trainers program developed to train a group of people to be champions of awareness programs in communities. The trainees from these trainings then assisted NOLA in the community awareness programs. Consultations with NOLA confirmed that 10 villages have been covered in awareness programs under the Samoa Disability Program thus far with many more still ongoing;
- b) training of Government officials to strengthen understanding on the CRPD and the role of the Government on the implementation of CRPD throughout various sectors;
- c) compiling training packages (from these trainings) which are used in awareness programs and workshops. Further, materials and resources which include child friendly booklets were made readily available in both languages for the public.⁹⁵ Due to resources constraints these materials could not be made available in accessible forms such as braille;
- d) celebrating the International Disability Day by the Government adding further recognition and awareness amongst all levels of the community and encouraging their participation in activities aimed at increasing awareness. One of the activities was the competitions which targeted schools on the need of people with disabilities; and

⁹¹ See Article 8 of the CRPD.

⁹² Policy Outcome 1 of the NPPD 2016-2020 focuses on empowering people with disabilities to promote and advocate for their human rights. See pg. 12.

⁹³ This Program is funded by the Government of Australia is a 4 year program which focuses on 4 Outcomes. See pg. 2 of the NOLA SPD Annual Report 2014-2015.

⁹⁴ Outcome 2 of the SDP seeks to ensure that deeper community awareness of and support for the rights of all people with disability and their increased social inclusion are achieved. See pg. 2 of the NOLA SPD Annual Report 2014-2015.

⁹⁵ See <http://dfat.gov.au/about-us/publications/Documents/samoa-disability-program-annual-newsletter-2014-15.pdf>. Accessed 29 June 2016.

- e) raising awareness through the engagement of the media and the use of various information methods such as billboards, TV sign language interpreting program, banners to name a few as confirmed in the consultations with NOLA and MWCSO.

These efforts by Government and NGOs are to be commended considering the progress Samoa has made in recognizing the inclusion of the needs, participation and rights of people with disabilities. The findings from the Survey support the current situation that the community is receptive and accepting of people with disabilities and the issues relating to them.⁹⁶

Although this is a significant progress towards greater awareness, findings from consultations as well as focus groups discussions and home visits highlighted that awareness is far from being realized or practiced. It is the view of the Office that issues addressed below must be taken into consideration by the Government to ensure that people with disabilities fully enjoy their rights without negative interference of the environment in which they live.

Educating family members/carers

“It’s very hard to care for her illness, when she is mad at something we can’t handle her, the only thing is to smack her because we don’t understand why she is mad or angry”

“It is really difficult to look after people with disabilities particularly those with intellectual disabilities because you never know what they want and they have behavioural problems that are hard to deal with...”

“T has down syndrome...” my son is sick but my wife mostly cares for him so I’m not really familiar with his illness...my wife has to take him everywhere she goes.”

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.

Although the families/carers respect the rights of their relative with disability, the way in which they care and protect their relatives unconsciously creates a barrier for the person with disability. It encourages the behavioural norms of dependence which hinders the ability of people with disabilities to realise their full potential thus preventing their full participation in society.

“I love to play rugby but I’m not allowed to because my parent thinks I might get a seizure and die if I play...”

“The fact that he is unwell we don’t expect him to do any chores, we have already instructed our children who are able that if God were to take us soon, they must take care of their brother because he is unwell, they must love him and cater for his needs...God will bless them through their sick sibling”

⁹⁶ See http://www.samoobserver.ws/en/17_12_15/local/323/Disability-advocates-honoured.htm. Accessed 29 June 2016.

Therefore, training that targets family/careers of people with disabilities is crucial in order to foster greater understanding of the medical impairment to equip the carer to provide better assistance. Furthermore, the role of family members caring for people with the disabilities is critical in developing a conducive environment in empowering people with disabilities. It is critical that family members are educated through provision of awareness and information to encourage the empowerment⁹⁷ of people with disabilities so they can participate and be in control of their lives.

Attitudinal Barrier

Views obtained from the participants of focus discussion groups reflected the negative perceptions on the myths of disability in society. The participants in the Survey noted that the causes of disability is associated with health complications during pregnancy or caused by a “curse”. During home visits with families of children with disability mostly expressed that it is “Gods will” not a curse.

Furthermore, there was a common view from the participants that people with disabilities should only have the freedom to make their own choices in life if they do not have an intellectual impairment.⁹⁸ Furthermore, many expressed that people with disabilities are well respected in village and in church settings hence they are treated as “special” and are not expected to make decisions as these obligations deem too much for them because they are “sick”.⁹⁹

“If they have physical disability but their brain works fine then it’s good but if they are mentally unwell then no they should not be able to make decisions because they wouldn’t understand the decisions they are making”

“It all depends on the sickness, if they have a psychosocial disability they are unable to make decisions in villages or church because they are sick”

“They can be part of committees or things in church and village but they shouldn’t be expected to make any decisions because of their illness..It would make them even sicker from stress of decision making”

Although they can be part of the church committee or village councils they are expected to be seen and not heard which in many ways can lead to marginalisation.

Capabilities and contribution of people with disabilities to society

There is a common perception across the focus groups discussions that people with disabilities are unable to work and provide for themselves because of their impairment particularly if the person has an intellectual disability. The CRPD provides avenues and conditions to encourage participation regardless of the severity of the person’s impairment and encourages the perception that everyone is capable and can make a contribution to society. Hence, Article 8 of the CRPD requires government to ensure that public awareness activities are not only designed to promote positive perceptions and increase social awareness towards people with disabilities, but are also significantly designed to promote recognition of the skills, merits and abilities of people with disabilities, including the contribution they can make to the workplace and the labour market and in the context of Samoa, the development of their families, communities and church.

⁹⁷ SVSG notes that they have already started support for people with disabilities in the community include caregiving. Based on the identified need to train family members to provide this support, SVSG in 2016 started a Caregivers training, which has sought Non Formal Learning recognition with the Samoa Qualification Authority.

⁹⁸ Focus Group discussions on file at the Office of the Ombudsman.

⁹⁹ See *Ibid* 99 above.

NOLA and MCIL carried out trainings in Upolu and Savaii on the benefits of people with disabilities in the workforce. MCIL stated that despite these workshops¹⁰⁰ being targeted for people with disabilities there was exceptionally a low number of people with disabilities who actually participated.

“I am 20 years old and I have an intellectual impairment...I work at one of our local beach fale to clear the rubbish every morning to help my parents with our church and village obligations...”

“P is 36 years old with an intellectual impairment who attended Loto Taumafai where he learned how to do simple carpentry work. He helps out a lot around our house... he assists me with our plantation work and he fixes our broken chairs, pantry, kitchen.

L has down syndrome. “I teach her how to weave a fine mat so whatever happens to me at least she can do this to earn a living and be independent”

Services available for people with disabilities

There is a lack of awareness regarding the services that are available for people with disabilities residing in Savaii as well as in rural areas of Upolu.¹⁰¹ A large majority of the participants in consultations including families of children with disabilities were not aware of services available to people with disabilities such as the free prescription of medication. The majority of the known services are regularly provided by NGOs such as Loto Taumafai, SVSG and SENESE.

“J is 26 years old, he is deaf and mute, he has never been to school. The only way he could communicate is by reading lips as he has never been taught sign language. The family says that there hasn’t been an opportunity for him to learn sign language as they live in Savaii and no service in Savaii to provide such education.”

Recommendations:

- 6) NOLA in collaboration with MESC should ensure that all schools are covered in the awareness programs that targets children and teachers.**
- 7) NOLA in collaboration with MWCSO and the community networks (e.g STN, SN, Youth and Church) should increase their efforts in raising awareness within the family unit about the rights of persons with disabilities.**
- 8) MCIL, PSC, MWCSO, in collaboration with NOLA and Chamber of Commerce should carry out more awareness raising activities to promote the capabilities of people with disabilities in the employment sector and the contribution they can make in the development of their communities.**

¹⁰⁰ MCIL consultation, 4 April 2016 on file at the Office of the Ombudsman.

¹⁰¹ Focus Group discussions on file at the Office of the Ombudsman.

4. Health

This section is not a comprehensive analysis of health rights for people with disabilities, but rather, it focuses on crucial aspects of health rights for people with disabilities that were identified during consultations.

Health is defined by the World Health Organisation (“WHO”) as a “state of complete physical, mental and social well-being, not merely the absence of disease or infirmity.”¹⁰²

The WHO establishes the importance of the right to health in its Constitution where it states:

“The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, political belief, economic or social condition . . . Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.”¹⁰³

4.1 Health in the CRPD

Article 25 requires government to provide free or affordable health care¹⁰⁴ to ensure that people with disabilities are able to make independent and informed decisions about their health.

Further, the right to health is closely linked to the right to habilitation and rehabilitation in Article 26. Habilitation and rehabilitation includes a range of physical, vocational, educational, training related measures which seek to assist people with disabilities to enjoy independence and the ability to participate freely in society. Article 26 requires government to provide a range of health services including allied health services such as physiotherapists, occupational therapists, speech pathologists, orthotists/prosthetists and social workers who all provide input and advice on the rehabilitation process.

4.2 Current Legal and Policy Framework

It appears that the *NHS Act* and relevant regulations may not specifically provide for free and affordable health care services for people with disabilities. However, on the NHS website, it says that NHS provides free health care to people with disabilities.¹⁰⁵ Despite what it says on the website, NHS did not seem to be aware of such a policy during consultations with the Office.

¹⁰² See <http://www.who.int/about/mission/en/>. Accessed 29 June 2016.

¹⁰³ See *Ibid* 103 above.

¹⁰⁴ Free and affordable health care to (i) sexual and reproductive health; (ii) population-based public health programs; (iii) health services needed by people with disabilities, including early identification and intervention; (iv) health services as close as possible to people’s villages, including in rural areas; (v) access to independent and informed decisions about their health; and (vi) non-discrimination regarding the denial of health care, food, fluids and health insurance on the basis of disability. See Article 25 of the CRPD.

¹⁰⁵ The services that are free of charge include: outpatient consultation and treatment, whether it be an Accident & Emergency, General Outpatient or Outpatient episode; admission services inclusive of bed stay, meals and any treatment administered and surgery; diagnostic laboratory and medical imaging tests conducted as an inpatient; pharmaceuticals required whilst in hospital. See <http://www.nhs.gov.uk/index.php/89-home/nhs/119-service-directory#FCHS>. Accessed 20 May 2016.

Habilitation and Rehabilitation

The *Allied Health Professions Act 2014* sets up a system of registration for allied health professionals which includes Clinical Treatment Services, Complementary and Health Alternative Therapies, Traditional Health Practices, Population Health Services, Mental Health and Wellbeing and Applied Health Science Services.¹⁰⁶

Psychosocial Disability

The *Mental Health Act 2007* (“MH Act”) provides for the care, support, treatment and protection of persons with a mental disorder and for related purposes. The *MH Act* defines a person with a mental disorder as a person with a mental illness which is a medical condition caused by various factors detailed in the Act. The *MH Act* defines the objectives and key areas for action of the Mental Health Unit which is responsible for providing care and treatment services for persons with mental disorder. The Office wishes to highlight at this point that the internationally recognised term under the CRPD to be used for people with mental disabilities is “Psychosocial” disability. Psychosocial disability relates to the ‘social consequences of disability’ - the effects on someone’s ability to participate fully in life as a result of mental ill-health.¹⁰⁷

4.3 Current Situation

Free and Affordable Health Services

The Disability Unit is going to develop and implement a system for the issuing of “disability ID cards” that will provide the holder access to free health care.¹⁰⁸ It is the opinion of the Office that in keeping with the human rights based approach this card should be called a health care card for people with disabilities. The Office is very supportive of this proposal, however, it is unclear in the policy what the criteria will be to receive free medical care, whether this card will allow for subsidised medicine, and how the card will be funded.

“The biggest challenge for our family is the cost of her daily needs and her medications...it would be great for the Government to provide free medication for people with physical impairment like they do for pensioners...it would help us alot...”

From the focus group discussions and home visits, participants stated that they are paying for their medication and health related services. They further raised concerns that the cost of health care has a disproportionate effect on people with disabilities and their families as they often need to see doctors and health professionals much more regularly than people without disabilities. These costs are enhanced by incidental costs such as transport costs (for those in rural areas) as they have to travel long distances and sometimes from Savaii to Apia via ferry and bus to see the health professionals at the hospital in Moto’otua.

However, there appears to be some form of subsidised healthcare which is provided by NHS for people with psychosocial disability. The issuing of the card is at the discretion of the doctor and there seems to be an uncertainty about what constitutes ‘disability’ for the purposes of a disability subsidy card. It is the view of the Office that the definition of disability to be adopted will be crucial in facilitating the policy decisions on this matter.

¹⁰⁶ See the Schedule of the *Allied Health Professions Act 2014*.

¹⁰⁷ See *Ibid* 107 above.

¹⁰⁸ See NPPD 2016-2020 at pg. 14 & 24.

Habilitation and Rehabilitation

There are currently very few local allied professionals in Samoa. NHS currently employs one physiotherapist and two physiotherapy assistants which is inadequate compared to the population of Samoa. From consultations with NHS, it appears that allied health services is not one of their key priorities and therefore there is no gradual build-up in the ongoing strengthening of these services. Consequently, the state of allied health care and the provision of multi-disciplinary health services in Samoa is poor. However, two Australian allied health volunteers (speech pathology and occupational therapy) are currently engaged with NHS to develop and define the roles and responsibilities of these services.

More needs to be done to encourage young Samoans to pursue careers in allied health and obtain relevant training in this field particularly from overseas institutions since it is not offered at NUS. This will mean that the NHS, in collaboration with MOH, need to ensure that scholarships from regional partners such as Australia and NZ include scholarships relating to the allied health professions. Such scholarships should include a clinical study period, for students to work in the host scholarship country to gain clinical experience before returning to work in Samoa.

In other cases, the NGOs such as Loto Taumafai and SVSG provide, within their resources and skills, rehabilitation and habilitation. The case study below illustrates such work.

Psychosocial Disability

Psychosocial disabilities or mental disability are included in the definition of 'disability' within the CRPD where it states that "people with disabilities include those who have long-term physical, *mental*, intellectual or sensory impairments." However, many people in Samoa do not consider psychosocial as a disability. During the course of community consultations and focus groups, people described all forms of psychosocial disabilities as simply 'brain fever' or the person being "possessed with demons."¹⁰⁹

The *Samoa Mental Health Policy 2006* states that the family is the natural and appropriate health care setting for the promotion of mental health and the management of health disorders, with the exception of some severe disorders requiring hospitalization or seclusion."¹¹⁰ However, the following case study Z shows that many families do not know how, or do not have the support, to look after their relatives who have psychosocial impairments.

Case Study: Z

Z was in high school when she started showing strange behaviour and not communicating properly. Z's family reacted negatively towards her by telling her off and pushing her for misbehaving. It was probably 6 months after Z's strange behaviour that the family realised that there may be something wrong with her. So they took her to the hospital and the hospital gave her some medication. She was supposed to be admitted to the Mental Health Unit but the family made the decision to care for her at home. The Mental Health Unit would occasionally visit X at home like once a month.

After four (4) years, Z's medical condition was finally given a proper assessment by a doctor visiting from NZ and was diagnosed as having schizophrenia. The Mental Health Unit in Samoa were able to make some changes to Z's medication and Z started showing some improvement. However, there were occasional relapses where she would become violent. Z's family unable to deal with the violence, considered moving Z into the care of the Goshen Trust. Z was then admitted

¹⁰⁹ Focus Group discussions, on file at the Office of the Ombudsman.

¹¹⁰ See pg. 3 of the *Samoa Mental Health Policy 2006*.

to Goshen Trust and has been with Goshen Trust in the past 4 months where she is receiving a regular dosage of her medicine and regular blood tests to monitor the side effects.

Since she has been admitted into Goshen Trust, Z has shown improvement. Initially she was unable to take part in the Goshen Trust group activities but through her regular medication and tailored program she is now able to interact with the other residents through art, exercise, horticulture and more.

The Policy also highlighted the challenges faced by the Mental Health Unit at that time such as the lack of psychiatrists as they have been coming and going over the years, the lack of medicine and proper facilities (such as space to keep patients, psychiatric beds, etc). Consequently, the cornerstone of the psychosocial assessment and treatment had been largely dependent on Specialist Nurses. It was also noted by the Mental Health Unit in recent consultations for this report that there is a priority need for a psychiatrist. Furthermore, the Mental Health Unit only offers the psychosocial assessments to acute psychosocial disabilities, where a person needs care as an inpatient in hospital for a period of time or intensive support through a home treatment team in the community.¹¹¹ However, there may be many other types of psychosocial disabilities which are not diagnosed or not properly diagnosed which results in psychosocial disability not being treated. This service is offered for Samoan citizens free of charge.

The Mental Health Unit also extends its services to the Samoa Prisons and Corrections Service (“SPCS”) on some occasions where they visit the prisons to carry out assessments of prisoners who may have or suspected to have psychosocial disability.

Some of the patients which are diagnosed by the Mental Health Unit are referred to the Goshen Trust Mental Health Services Samoa (“Goshen Trust”) which provides respite care for these patients. However, as shown by the case study below, no funding is provided by the government to Goshen Trust so that they can provide these services. The state is the primary duty bearer in relation to the diagnosis, treatment and family support for people suffering from psychosocial disabilities and yet it is not currently meeting this responsibility, shifting it instead to a volunteer based organization. The Government must either choose to adequately fund and increase the capacity of Goshen Trust or take full responsibility within the NHS for persons with psychosocial disabilities and their families.

The Mental Health Unit has indicated to the Office that it is considering the amendment of the *MH Act* in order to comply with the CRPD. These provisions relate to involuntary and voluntary orders, as well as the administration of property for people with psychosocial issues. The Office shares this view and believes that this should be examined as part the LCR.

Case Study: Goshen Trust Mental Health Services Samoa

Goshen Trust Mental Health Services Samoa is a non-profit organization established in 2009 with the main goal of providing care and support to people who suffer with psychosocial disabilities and their families. Key activities of the organization include providing residential treatment facilities, family community support and up-skilling members, especially families, in mental health care. However, the Goshen facilities can only accommodate up to 10 in-patients at any one time despite their estimate that the need across Samoa is far greater.

Goshen is supported by Penina Health Trust, NZ volunteers and families but it does not receive any direct support from the state despite receiving patient referrals from the NHS mental health unit. Goshen is currently working with 34 families of those suffering from psychosocial disabilities that have been referred by the NHS.

¹¹¹ Acute mental illness is characterised by significant and distressing symptoms of a mental illness requiring immediate treatment. This may be the person's first experience of mental illness, a repeat episode or the worsening of symptoms of an often continuing mental illness. The onset is sudden or rapid and the symptoms usually respond to treatment.

Other concerning issues

The following are some of the concerns that were identified during consultations and focus group discussions that the Office wishes to highlight for Parliament's attention.

Early Detection and Intervention

B is now 10 years old and has a hearing impairment... "My husband and I only discovered that she is sick around 2 years old, we were told by the hospital that it's normal for some kids to develop slowly but years went by and nothing changed"

"My son was born normal, there were no signs of any illness that we could tell, and he was a healthy boy until he was 9 years old. One day he suddenly became really sick with a fever and started to have an attack. When we took him to the hospital they said he had suffered from brain fever and explained to me what to do when he has another attack...Since then, his seizures are now permanent and regular...we've learn to treat it so no need to take him to the hospital"

The consultations and home visits highlighted that there are no adequate early detection and intervention systems in Samoa. The responses from the community consultations noted that babies (in early stages of life) who suffer fits, fever, cold and who were taken to the hospitals were commonly diagnosed with brain fever (*fiva faiai*). In other cases, the disabilities were seen by the family as a result of the will of God, or punishment for the sins and misdeeds of family members. In other cases, families do not have the financial means to take the babies to the hospital. For these reasons, the babies are not taken to the hospital and consequently, these children are sometimes not diagnosed at all. These are the people with disabilities that fall through the cracks and do not have their disability detected and diagnosed in the early stages of impairment.

In consultations with NHS, the normal clinical protocols are used to detect any abnormalities in unborn and newborn babies measuring growth against the typical development stages. If the baby does not meet the proper development stages and the doctor identifies an abnormality, they look into these matters of disabilities. Aside from this, there is no specialised method to detect specific forms of disabilities.

Over the course of the consultations with relevant stakeholders, it appears that one of the most successful intervention programme available under NHS is the Diabetic Foot Clinic which is administered by the MDS with initial support from Motivation Australia. This clinic seeks to prevent lower-limb amputations by treating and dressing the wounds on the feet of patients diagnosed with diabetes. NHS advised that nurses are trained in early detection and intervention methods when they study their Bachelor of Nursing at National University of Samoa ("NUS"). Local NGOs such as Loto Taumafai also conduct early intervention and detection services as part of its outreach programme.

Inadequate detection and intervention at the early stages of impairment, especially in terms of psychosocial and intellectual impairments, appears to be an issue in determining the precise prevalence of disability in Samoa. In many cases people with disabilities, have never been properly diagnosed by a health professional. Early detection and intervention of disability is crucial as many impairments can be treated and rehabilitated if diagnosed early.

Lack of Proper Diagnosis

“He was a healthy boy, he went through normal stages of development like other children at 1 year old, he was able to walk and mime a few words until one day he got sick with diarrhoea. He was taken to the hospital and was prescribed paracetamol, antibiotic and an oral rehydration salts (ORS). A few days after he took his prescribed medication he suddenly became inflexible and couldn't move. He was taken to the district hospital where he was kept for 3 days waiting for an available ambulance to transfer him to Tuasivi Hospital. At Tuasivi we were told by the doctors that he may have brain cancer. They monitored him for two weeks, gave him some injections and continued wrapping him with cold towels...After two weeks at Tuasivi they transferred us to Motootua Hospital where he continued being injected however they told us not to wrap him with cold towels. We were at Motootua for almost 3 months and my husband and I didn't see any changes to his condition so we decided to take him home and seek the advice of a traditional healer. He is now 4 years old and after a few years receiving massages from the traditional healer he can make movements to his lower and upper body. What upsets us was no one at the hospital really explained to us what the injections were or what exactly my son's condition was...and to this day we still do not know what happened to him and what caused him to be cerebral palsy...and now every time he gets sick we are scared to take him to the hospital.

The community consultations and home visits highlighted that one of the biggest barriers that currently exist for people with disabilities in Samoa, is that disability itself is not being properly diagnosed. Many participants during these consultations (both people with disabilities and their carers) claimed that they, or their family members, had never seen a doctor since the impairment because of:

- a) the lack of health professionals; and/or
- b) the lack of access to a specialised health professional or to a health clinic especially in the rural area as the paediatricians and psychiatrist are based in Apia who occasionally conduct clinics at Tuasivi Clinic in Savaii; and/or
- c) financial constraints; and/or
- d) superstitious beliefs.

Therefore, many people with disabilities in Samoa go undiagnosed or do not get their disability properly diagnosed. There were a number of cases where people with disabilities and their carers could not say what the medical condition the person had or what caused the impairment. The lack of proper diagnosis leads to families not fully understanding the impairment of their relative, which can in turn lead to people with disabilities not gaining access to the appropriate health services they need. Given the lack of diagnoses in Samoa, it is unsurprising that many families and carers do not know how to adequately care for their loved ones who have disabilities.

To assist these families to care for their relatives with disabilities, the service providers such as Special Olympics Samoa, Loto Taumafai, SENESE, SVSG and Motivation Australia all provide educational components in their outreach programs. For example, Loto Taumafai provide information to carers of people with disabilities on how to look after people with disabilities who are completely bed-ridden. Motivation Australia, Loto Taumafai and SVSG offer assistance to people in wheelchairs to repair and maintain the chairs.

In other cases, the home visits demonstrated that the lack of proper or incorrect diagnosis have resulted in families doubting and mistrusting the health professionals and has discouraged them from seeking further necessary medical attention for their relatives. Consequently, the families resort to other means

of providing a cure for their relatives with disabilities such as traditional healing, medicine and divine intervention.

Recommendations:

- 9) **The NHS and MOH should ensure that people with disabilities have access to free or affordable health care in Samoa via the implementation of a subsidy card for people with disabilities.**
- 10) **The NHS and MOH should collaborate to develop a strategic plan to increase allied health services and undertake awareness raising activities in schools promoting the roles of allied health professionals.**
- 11) **The NHS should consult with the OAG about how the *MH Act* should be amended so that it is compliant with the CRPD.**
- 12) **The Government should provide funding to the Goshen Trust so that the can adequately provide services for people with acute psychosocial disabilities.**

5. Education

Case Study: W- *“What is the point of him going to school when he is not even learning a thing nor is the teacher willing to give him the time of day to try and help him learn”.*

W is 13 years old who lives in Savaii. He has a serious intellectual impairment. He used to attend a public primary school from years 1 – 5 because there is no special school in Savaii. His mother’s daily routine when W was in school, was to take her son to school and wait there until school ended to bring him home. During this time, she noticed with sadness and concern that her son’s teacher did not pay much attention to him and he was left on his own. Because her son did not do anything most of the time, he became bored and became agitated and would throw tantrums. One of the days that W became unsettled and threw a tantrum, W’s mother decided to keep her son at home as the teacher told her that her son was becoming a bother during class. She saw no point in taking her son to school because he was not learning anything.

So for the past 4-5 years, he has been staying at home because of how W was treated by the teachers. The only education he receives now is through Loto Taumafai’s Early Intervention Community Based Program. Loto Taumafai’s program provides home school for students like W who are unable to attend school. This is the only time W is exposed and participates in any educational activities which occurs once a month.

Although, it may be challenging for Samoa (in the short term) to transition from a segregated education system into an inclusive education system, in the long run an inclusive education system is generally less expensive than a segregated education system.¹¹²

5.1 Education in the CRPD

This case study highlights the obligations which government must comply with under the CRPD particularly Article 24. Article 24 seeks to reaffirm, clarify and expand the right to education¹¹³ to ensure that people with disabilities participate and become inclusive in the general education system together with people without disabilities.

¹¹² Anonymous participant from the Home Visits- Mother of child sharing her experience’, Savaii March 2016, on file of the Office of the Ombudsman.

¹¹³ See Article 28 of the UDHR; Article 18 (4) of the ICCPR, and Articles 23 and 28 of the CRC.

Inclusive education is:

“Inclusion is a process that recognizes: (a) obligation to eliminate barriers that restrict or ban participation, and (b) the need to change the culture, policy and practice of the mainstream schools to accommodate the needs of all students including those with impairments”. It requires “accommodating both different styles and rates of learning and ensuring quality education to all through appropriate curricula, organizational arrangements, teaching strategies, resource use and partnerships with the communities.”¹¹⁴

Upon the ratification of the CRPD, government needs to show that it has a strategy in place to achieve inclusive education – putting in place their resources with the view of taking steps towards achieving this.¹¹⁵ It also recognizes that a government which has a segregated or dual education system (like Samoa), that a special school which provides education for people with disabilities cannot be immediately closed because it would discriminate against the students with disabilities. However, government must work towards a gradual approach to build a system of inclusive education while the special schools continue to function. Realistically there may be children with severe disabilities and multiple limitations that cannot be included in the general education system. Therefore, Article 24 does not prevent a party from establishing a special school for these children provided that it is done on the basis of the barriers to their participation.¹¹⁶ This is reflected in the IESPLD prepared by MESC that some children with extensive disabilities cannot participate in a regular school.¹¹⁷

In order for this right to be fully realised, reasonable accommodations and support measures must be implemented by government. The reasonable accommodation and support measures for each student depends on the needs of the student and these will have to be discussed with the student, the parents or carer, and the educational institution.¹¹⁸ Failure to make reasonable accommodation constitutes discrimination on the basis of disability and prohibited with immediate effect.¹¹⁹

Reasonable accommodation	Support Measures
<p>Necessary alterations or modifications of the physical environment to meet the special needs of people with disabilities such as making the buildings accessible through the use of ramps, installation of elevators and constructing wider entrances and hallways.</p>	<p>Measures which supplement the reasonable accommodation focusing on the individual by adapting the general education system in order to include all children by focusing on the learning capacities of every child and establishing targets that suit the needs of all such as the teaching methods, curricula and the evaluation tools. It also includes the necessary equipment and material provided in the appropriate forms of communication such as braille, sign language or screen-reading technology, provision of supplementary classes, special tutors and support staff.</p> <p>Example: Case Study W</p>

¹¹⁴ The Right to Inclusive Education According to Article 24 of the CRPD: Background, Requirements and (Remaining) Questions, Gauthier De Beco, Netherlands Quarterly of Human Rights, Vol. 32/3, 2014, Netherlands.

¹¹⁵ See *Ibid* 3 above.

¹¹⁶ See *Ibid* 3 above.

¹¹⁷ See *IESPLD* at section 2.4, pg. 9

¹¹⁸ Human Rights: YES!, Action and Advocacy on Human Rights of Persons with Disabilities, second edition, Janet E. Lord et al, University of Minnesota Human Rights Centre.

¹¹⁹ Thematic Study on the Right of People with Disabilities to Education, Report of the Office of the United Nations High Commissioner for Human Rights, 18 December 2013 (Tabled in Human Rights Council 25th Session)

5.2 Current Education System in Samoa

Samoa currently has a segregated or dual-education system, with special schools for children with disabilities such as Loto Taumafai and Aoga Fiamalamalama. Aoga Fiamalamalama focuses on improving the inclusivity of people with intellectual impairments and Loto Taumafai provides education to children with hearing, intellectual and physical disabilities.¹²⁰ The data provided by the MESC showed that a total of 206 people with disabilities were being taught in the general education system. Of this total, 181 were enrolled in primary schools but 25 in secondary schools.

In addition, there are two private service providers which are:

- a) **SENESE Inclusive Education** – is an inclusive education provider in partnership with the MWCS and MESC. It works with children with disabilities from 0-18 years by providing educational support services through making available teacher aids and resources to assess and assist students to access appropriate learning skills such as auditory learning skills, sign language and braille; and
- b) **Samoa Blind People Association** – it works with children who are fully blind or who have visual impairments. It involves teaching children how to read and write Braille in order for these students to attend regular schools. The Association continues to provide support to these students when they are enrolled in regular schools – through collecting notes from the teachers and transcribing it in braille so the student can read.

5.3 Current Legal and Policy Framework

The *Education Act* recognizes and allows for the “inclusive education of person(s) with special needs” or people with disabilities to participate in the general education system.¹²¹ The *Education Act* authorizes the Chief Executive Officer (“CEO”) of MESC to take necessary actions such as directing that a compulsory school aged child¹²² with special needs be enrolled at a school that would provide the appropriate education for the child. Furthermore, the CEO must establish guidelines or policies for schools in respect of special needs of the child such as the assessment criteria, modification of teaching program and the level of training required of teachers and any other matters relating to the education of children with special needs.

In support of the *Education Act*, MESC has also developed and finalised in principle the *IEPSLD*.¹²³ The *IEPSLD* was developed to respond to the needs of students with disabilities. The vision of this Policy is to provide a national inclusive education system that satisfies basic learning needs of all children and adults of diverse characteristics and backgrounds. Some of the principles which underpin the *IEPSLD* are as follows:

- a) it is a basic human right for all children to have the right to learn and be educated; and
- b) meeting the needs of all learners with particular emphasis on promoting policies, strategies and practices that address existing inequalities; and

¹²⁰ It currently has 129 students ranging from the ages of 5-18 who are divided into two levels¹²⁰ of Primary and Secondary. Vocational training is also provided for 9 students.

¹²¹ See sections 19, 58 (4) and 61 of the *Education Act 2009*.

¹²² Section 2 of the *Education Act 2009* defines a compulsory school-aged child who is between 5-14 years of age who has not completed Year 8 of school.

¹²³ In consultation with MESC, it advised that the *IEPSLD* has been approved in principle by Cabinet with the understanding that the Ministry to closely examine the policy if there are areas of concern that need to be raised and then to resubmit to Cabinet. There is an Inclusive Education Sector Task Force that is working on this exercise now, to develop an implementation plan for the *IEPSLD*.

- c) students with disabilities will require reasonable and in some cases significant adjustments related to their specific impairment areas in order for them to have effective access to education.¹²⁴

The *IEPSLD* further acknowledges the right to education under the CRPD and the inclusion of children with disabilities in the general education system. Therefore, it appears that MESC has considered the obligations Samoa must meet under the CRPD in order to realise inclusive education such as:

- a) combating negative attitudes and stigma attached to disability by the school staff through more awareness to better understand and know people with disabilities; and
- b) adjustment must be made to building access, the curriculum, learning programmes (which require specialist assistance) and Individual Education Plans; and
- c) maximising the opportunities for children with disabilities for example full-time regular class with a full-time teacher aide as co-teacher in a supportive role; and
- d) increasing skills and competencies of disability sector workers particularly the teachers.

The MWCSO in its *NPPD 2016-2020* also highlights the importance of inclusive education and the mechanisms for combating barriers associated with it in order to achieve inclusive education.¹²⁵ In terms of barriers, the *NPPD 2016-2020* notes (amongst other things) that MESC will need to revive¹²⁶ the Inclusive Education Development Program,¹²⁷ review the methods of assessment for tests and exams for students with disabilities, develop minimum service standards for early childhood care and education with emphasis on accessibility (railed walkways, toilet facilities).¹²⁸

5.4 Current Situation

Children with Disabilities not attending school

While Samoa has in place an Act and policies which seek to allow and promote inclusive education, the practical implementation remains a concern. It was evident from consultations and home visits that there were children with disabilities who still do not attend school. There is no data available to confirm the exact number but Loto Taumafai in its records noted that approximately 110 children that they visit at home do not attend school.¹²⁹ Furthermore, out of the 120 families the Office visited about 90% of the children with disabilities do not attend school and are kept at home.¹³⁰

Lack of co-ordination and skilled teachers

A recent report¹³¹ focusing on the Inclusive Education for Samoa and other Pacific countries noted that,

“At present, the implementation of disability-inclusive education has been challenging due to a lack of understanding and clarity of what constitutes IE and disability-inclusive education. This in turn has impacted on teacher roles, provision of resources and in some cases, parental attitudes.”

¹²⁴ See *IEPSLD* at pg. 9.

¹²⁵ See *NPPD 2016-2020* at pg. 9.

¹²⁶ The Australian High Commission has confirmed that the original program was called the Samoa Inclusive Education Demonstration Program but it is now known as the Samoa Inclusive Education program. Furthermore, it has now transitioned under DFAT support to the Education Sector through Sector Budget Support

¹²⁷ See *NPPD 2016-2020*, at pg. 9 & 15.

¹²⁸ See *NPPD 2016-2020*, at pg. 16.

¹²⁹ Loto Taumafai consultation, 5 February 2016, on file at the Office of the Ombudsman.

¹³⁰ A review of the number of families visited is found in Annex A, the large majority of this number was found during home visits in Savaii.

¹³¹ Hitendra Pillary et al, *National Profiles of In-Country Capacity to Support Disability-Inclusive Education, Fiji, Samoa, Solomon Islands and Vanuatu* at pg. 32.

MESC noted in the consultations that the reasons attributed for the lack of success in the implementation of the *IEPSLD* is because MESC lacked the capacity and expertise to coordinate the implementation. Even if MESC had the manpower and capacity, the implementation of the *IEPSLD* is not possible as there are no qualified and skilled teachers to facilitate it.¹³²

“There was a teacher who taught at the school who used to teach at Loto Taumafai... he was really good with my daughter and understood her needs well...He gets her involved in the learning and she would come home with homework... but then that teacher left and that stopped...they said she is a slow learner and her behavioural problem is becoming an issue in school for other children”

“M has an intellectual impairment. He attended Loto Taumafai before his parents decided to enrol him in to mainstream school. One of the things they saw changed in him since he attended mainstream school was the change in his behaviour...”he suddenly became angry and aggressive all the time and we suspected that it may have been the lack of attention he received from the teachers or children teased him (crossed eyes)...we enrolled him back to Loto Taumafai”

In its effort to introduce inclusive education for the teachers, the Faculty of Education in the NUS confirmed that it only offers an introductory course in the first year of the Bachelor of Education Program (inclusive education). No further courses are offered later in this Program to build on this introductory course. Furthermore, the students are not keen to learn or continue learning in this field as it is difficult and challenging. Most importantly, NUS does not have the appropriate equipment or the appropriate capacity. In teaching this introductory course, NUS relies on the support of the inclusive education providers to assist with the specific parts of the introductory course which relates to Braille, Sign Language, etc.

In addition, the APTC has also offered some courses which cater for individuals who are currently employed in the field of disability¹³³ and those who hold management positions or seek to attain leadership positions in the field disability.¹³⁴ APTC hopes to offer a new course in 2017 relating to disability and sports but this is still in discussion with MESC.

Lack of Access to school buildings

On the other hand, it has also been identified¹³⁵ that the other major barrier in realising inclusive education is the lack of physical facilities (such as the buildings) and equipment. This barrier¹³⁶ may be difficult to address since some of the school buildings are funded by the villages themselves. Furthermore, there are no special transportation for people who use wheelchair to be transported from their homes to school.¹³⁷

¹³² Importantly, there was a Co-ordinator who was funded by the DFAT to assist MESC in co-ordinating the inclusive education providers and other stakeholders as part of implementing the *IEPSLD*. It was understood that the Government will take ownership of the position to be included as part of their organisational structure. MESC has indicated that Government has taken up the responsibility of funding this position and has since advertised this position. It is their hope this will lead to the employment of a Co-ordinator to spearhead the implementation.

¹³³ APTC offers Certificate III in Disability for those who are volunteering or working with people with disabilities in special schools, early intervention centers, etc. It has been offered over the past three (3) years.

¹³⁴ APTC offers Certificate IV in Disability which builds on from Certificate III. This program offers higher level skills and knowledge required for those in management positions working in a variety of Disability Services.

¹³⁵ Both the *IEPSLD* and *NPPD 2016-2020*.

¹³⁶ *NPPD 2016-2020*.

¹³⁷ Loto Taumafai consultation, 5 February 2016, on file at the Office of the Ombudsman.

Lack of Early Detection and Focus on Early Childhood Education

The other concern¹³⁸ is the need to have in place a detection, diagnosis and enrolment system in place for early detection to assist in determining the allocation of resources. The IEPSLD placed an emphasis on the establishment of an Inclusive Education Coordinating Unit within MESC to co-ordinate this process. From the consultations, MESC has confirmed that there is currently an Inclusive Education Unit under the Curriculum Division. However, it is unknown whether this Unit is active in the early detection of the disability of the child and his/her needs for the purposes of providing the necessary resources to facilitate her/his inclusion in the general education system.

Furthermore, some of the stakeholders raised the concern that there was a lack of focus on the Early Childhood Education. If the State focused on the development of the child from an early age in the early childhood education centres, children with disabilities would be more resilient and have better chances of being absorbed in the primary and secondary levels of the general education system. It is better to address the needs of the children with disabilities early in their educational lives rather than later particularly, when they reach secondary school. Therefore, the State needs to consider working more closely with or providing financial assistance to the inclusive education providers such as Loto Taumafai and SENESE to advance, improve and develop to promote the likelihood of inclusive education.

It may be challenging for Samoa (in the short term) to transition from a segregated education system into an inclusive education system, but in the long run an inclusive education system is generally less expensive than a segregated education system.¹³⁹ The realisation of the right to education is a prerequisite to leading a dignified and successful life,¹⁴⁰ inclusion and full participation in the society.¹⁴¹

“Students with disabilities should be taught together with children without disabilities so that they are not discriminated against...when you separate them it encourages discrimination, and children without disability will come to understand the needs of their class mates making them more aware and friendly towards the needs of people with disabilities as they grow up”

Recommendations:

13) MESC should prioritise the preparation of an Action Plan of how to achieve the IEPSLD including:

- a) set realistic timeframes;**
- b) identify the budget,**
- c) how to raise the capacity of the personnel (ie: the current teachers, teacher aides, student teachers),**
- d) reasonable accommodation through the universal design of educational facilities;**
- e) support measures (such as the appropriate curriculum, assessment and test criteria, teaching in the appropriate method through Braille, electronic readers, sign language);**

¹³⁸ See IEPSLD.

¹³⁹ The Handbook for Parliamentarians on the Convention on the Rights of People with Disabilities and its Optional Protocol (Handbook for Parliamentarians). See *Ibid* 3 above.

¹⁴⁰ See *Ibid* 4 above.

¹⁴¹ Thematic Study on the Right of People with Disabilities to Education, Report of the Office of the United Nations High Commissioner for Human Rights, 18 December 2013 (Tabled in Human Rights Council 25th Session).

- 14) MESC should work in collaboration with NUS to develop the current inclusive education course into a full program, and provide initiatives to encourage students to undertake this profession.
- 15) MESC should activate and strengthen the Inclusive Education Unit within MESC to implement the IEPSLD in coordinating with the service providers.

6. Employment

CASE STUDY: Vern, Employee of ANZ Bank (Samoa) Ltd

Vern completed his Bachelor's Degree in Education in 2013 at NUS and he couldn't wait to begin his career teaching primary school children. However, shortly after obtaining a job with MESC, Vern lost all feeling in his legs and was bed-ridden in Motootua Hospital for 9 months. Vern could not be diagnosed in Samoa because the MRI machine at the hospital was not operating at the time. Vern eventually travelled to New Zealand to undergo scans and was diagnosed with a tumour on his spine. The tumour has left Vern paralysed and in a wheelchair.

Once Vern became ill, he decided that working in a classroom with young children would be too difficult for him because his impairment had made him feel angry and frustrated. Vern resigned from MESC. Instead of feeling sorry for himself, Vern decided to apply for a job with ANZ Bank in Apia.

A new recruit at ANZ would normally start as a Bank Teller, handing out cash and helping customers make deposits. Vern could not be a teller because that position would require him to stand at his desk so he could assist customers. However, instead of refusing to give Vern a job because of his disability, the ANZ Bank decided to make accommodations for Vern by starting him off as a Customer Sales Consultant, a position which does not require Vern to stand up and which is located on the ground floor which is easily accessible for Vern in his wheelchair.

Vern's employment at the Bank has given him confidence and has made him happy again. Not only did the Bank give Vern a job, it also ensured that the handles on the doors were changed so he could access all the rooms on the ground floor of the bank. The Bank allows him time off so that he can see doctors and get more scans at the hospital. He feels like he is given respect when he is in the Bank, something that is not always given to people who have a disability. As Vern says "I would still be looking for a job if it wasn't for ANZ".

As Matt Fisher, CEO ANZ Bank Apia says "*We don't see Vern as a person with a disability, just as another employee*".

The right to employment is similar to the right to education, it has long been recognized in the Universal Declaration on Human Rights particularly in Article 23. CRPD Article 27 has, however, elaborated on this right to make clear that people with disabilities must have access to open, inclusive and accessible employment in the mainstream labour market.¹⁴²

¹⁴² Sabrina Ferraina, *Analysis of the Legal Meaning of Article 27 of the UN CRPD: Key Challenges for Adapted Work Settings*, pg.15.

6.1 Employment in the CRPD

The right to employment or the right to work under the CRPD asserts that people with disabilities have the right to:

- a) choose and accept the work of their own preference (either self-employed, employed in private or public sector) and are not discriminated against by virtue of having a disability;
- b) work in places that are open, inclusive and accessible to people with disabilities;
- c) be treated equally when they are at work such as equal pay, career advancement, be able to complain, and not be harassed;
- d) be able to work in safe and healthy working conditions; and
- e) make sure reasonable changes are made in the work place environment according to the personal needs.¹⁴³

It does not, however, guarantee that everyone, including people with disabilities, have full-time, paid employment. Instead, the “right to work” encompasses the right of all people to the opportunity to earn a living by freely choosing or accepting work and to undertake that work in safe and favourable working conditions.¹⁴⁴ In order to realise the right of a person with a disability, reasonable accommodation must be made.

Reasonable accommodation in the context of employment requires:

- (i) that the legal measures are in place to preserve this right such as ensuring that there are no laws which discriminates against the rights of people with disabilities to work; and
- (ii) by requiring employers to take positive steps to provide reasonable accommodation related to needs of employees and prospective employees who have disabilities such as ensuring buildings and workplace facilities are accessible; information and technology relating to work are in a form/means accessible to people with disabilities (such as in Braille or electronic reader).

6.2 Current Legal Framework

The *LER Act* prohibits anyone from discriminating¹⁴⁵ against people with disabilities, whether they are applying for a job if they are a current employee. This however, only applies to employment in the private sector. Furthermore, the *LER Act* also provides a complaint mechanism within MCIL by which people with disabilities who have been discriminated against on the basis of their disability can lodge complaints. Through consultations with the MCIL – it was confirmed that no complaints have been made to MCIL on this basis since the passing of the *LER Act*.

Further, Part 6 of the *LER Regulations 2015* (“Employment Regulation”), recognizes the rights of people with disabilities. *Employment Regulation 20* (1) requires the employer to modify the facilities to meet the needs of the people with disabilities if it is reasonable in the circumstances to do so. The *Employment Regulation* goes on to state that it is an offence if an employer contravenes this obligation. In relation to the employment of public servants, the PSC in consultations noted that in hiring its employees, it does not discriminate or differentiate between people on the basis of a disability. The appointment of any public servant is based on merits as expressed in section 36 of the *Public Service Act 2004*.¹⁴⁶ This merit-based appointment system according to PSC gives everyone (including people with disabilities) equal opportunity to be employed in the public service. According to PSC, since their

¹⁴³ Article 27 of the CRPD.

¹⁴⁴ James E Lord et al, Human Rights. Yes! Action and Advocacy on the Rights of Persons with Disability, University of Minnesota Human Rights Centre, at pg. 112.

¹⁴⁵ See section 20 (3) of the *LER Act*.

¹⁴⁶ Merits include (i) Skills and Abilities (ii) Educational Qualification (iii) experience and past work performances and (iv) Personal attributes.

system of recruitment is available to everyone, there has been no specific measures to assist or encourage the employment of people with disabilities.¹⁴⁷

Furthermore, if a person with disability is employed in the public service, the current and general understanding/practice is, it is solely the role of that Ministry/Office to cater to the needs of people with disabilities. The Ministry/Office should provide a suitable working environment, such as someone using crutches should be given enough space to be able to move around or someone who needed specific software so that they're able to use their computers due to their eyesight problems.

6.3 Current Situation

There is no data available to show the actual numbers of people with disabilities in the labour force. However, in reference to the NPPD 2016-2020, it noted that from the Labour Force Survey an estimated total of 2,750 employed people with disabilities – 24% of the total work force. However these figures cannot be taken as a true reflection of the people with disabilities who are employed, as this would mean that the total Samoan workforce is only eleven thousand (11,000) of the total population.

Low number of Employment

“People with disabilities should have the right to work only if they are physically fit but if they aren't particularly if they have a mental problem then no! They shouldn't work because they wouldn't understand their roles in that employment.. It would only make things harder for other staff..”

Although the number noted in the *Labour Force Survey*¹⁴⁸ is huge, it appears from the Office observation and consultations that there is a fair number of people with disabilities who remain unemployed. This may be attributed to employers assuming that people with disabilities may not have the capacity to perform the work, that they would be more of a liability to the company as they may either harm themselves or others in the workplace. In addition, the inaccessible workplaces, unavailability of information and communication in the appropriate form and lack of transportation may also limit the ability of people with disabilities and reduces the chances of such people to find suitable jobs, taking advantage of educational and training or commuting to facilities of all types.¹⁴⁹ Most importantly, the family members or carers of people of disabilities do not believe that their relatives with disabilities should find or be allowed to work.

Lack of awareness and access to employment

In conjunction with the legal measures, MCIL should carry out awareness-raising with the intention of removing barriers which exist in this context such as lack of understanding about the capability and capacities of people with disabilities; lack of accessible information about employment opportunities. By carrying out awareness programs, the Government will to an extent promote and improve employment opportunities for people with disabilities. This will also ensure that employment opportunities are secured for people with disabilities.

Further, in the Office's last report, it stated that despite the equal opportunity made available by MCIL to people with disabilities to access their jobs and apprenticeship programmes, there were no efforts

¹⁴⁷ It may also be important to note that the PSC confirmed that it does not maintain a disaggregate data of people with disabilities working in the public service. PSC consultation, 12 April 2016, on file at the Office of the Ombudsman.

¹⁴⁸ See *NPPD 2016-2020* at para. 4.3.

¹⁴⁹ ICESCR Committee, General Comment No. 5 'Persons with Disabilities' at para 22.

made to cater to the specific needs of people with disabilities. There are still no efforts. The CRPD calls for Government to ensure that people with disabilities have effective access to general technical and vocational programmes, services and training. MCIL should review the accessibility of their vocational training programmes in order to make them inclusive. Samoa should also consider ratifying the International Labour Organisation Convention 159-Vocational Rehabilitation and Employment (Disabled People) 1983 to promote open market employment opportunities for people with disabilities.¹⁵⁰

In consultations with the Chamber of Commerce as the national private sector organisation in Samoa, it noted that it carried out a training in early 2015 to raise awareness as to the employment rights of people with disabilities and also making the employers (in the private sector) aware of their obligations under the CRPD. People with disabilities have a right to be included in the labour market and employers have a responsibility to provide reasonable accommodations to ensure that the working environment is accessible to people with disabilities not only the work facilities but also their policies to capture the needs of people with disabilities.

Recommendations:

- 16) MCIL and PSC in collaboration with SBS should carry out an extensive survey to obtain disaggregated data on the number of people with disabilities who are employed to ensure their needs are catered for.**
- 17) Government should improve its efforts in creating job opportunities for people with disabilities through awareness within the public and private sector focusing on the benefits of employing of people with disabilities.**

7. Adequate Standard of Living and Social Protection

People with disabilities tend to have lower incomes and are more likely to live in poverty.¹⁵¹ This part of the report examines the need to assist people with disabilities in achieving an adequate standard of living and social protection. This is because people with disabilities often have extra disability-related costs such as assistive devices and medicine and often have higher rates of unemployment. The combination of higher living costs with the high rates of unemployment result in higher rates of people with disabilities living in poverty.

7.1 Adequate Standard of Living and Social Protection in the CRPD

Article 28 specifically addresses the right to a good standard of living and social protection without discrimination on the basis of the person's disability or impairment. It recognises that people with disabilities have the right to an *adequate standard of living* "including adequate food, clothing, housing, and continuous improvement of living conditions". Furthermore, people with disabilities have the right to *social protection* including access to clean water, affordable disability-related devices and services, programmes aimed at reducing poverty, and equal access for people with disabilities to retirement benefits and programmes. Most importantly, Article 28 also requires government to provide assistance to people with disabilities and their families who are living in poverty. This includes assistance with disability-related expenses such as medicine and assistive devices as well as training, counselling, financial assistance and respite care.¹⁵²

¹⁵⁰ See State of Human Rights Report 2015 at pg. 43.

¹⁵¹ United Nations Report of the Special Rapporteur on the rights of persons with disabilities, Catalina Devandas-Aguilar, A/HRC/28/58, 2 February 2015.

¹⁵² This includes planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to families who are caring for a child or an adult.

7.2 Current Situation

The *Fa'asamoa* provides its own form of social protection to its people with disabilities. As previously discussed, the care and protection that the family provides for their family members with disabilities creates a system in which there is a natural safety welfare net. In other cases, it appears that there is some form of assistance which provides grants or loan schemes specifically for people with disabilities which gives them a direct means of access to credit and assists them with everyday needs and allows them to operate projects and generate income.¹⁵³ Some support is provided for the assistive devices by MDS and NGOs, such as wheelchairs etc.

However, the Office observed from consultations and especially home visits that people with disabilities and their families/carers are struggling as a result of trying to meet the basic needs and incidental costs of disability such as medication, diapers, food (proper dietary). It does not help that there is a lack of free and affordable health care services for people with disabilities (refer to discussion in the Health section). This is confirmed by the SDPR that households with adults and children with disability are the poorest compared to other types of households' (such as households with adults with disabilities only, households with children with disabilities only, household with no people with disabilities). The report assumed that low income leads to more disability among children, or that having children with disabilities means less wealth accumulation by the household, because of the extra demand on time and expenses.¹⁵⁴

“My eldest child has a speech impairment and my youngest child is cerebral palsy...selling coconuts and crops from our plantation is our only source of income which assists us to cater for my sick children's daily needs including our other two children...sometimes when we don't make enough sales we struggle to meet their needs...We sometimes request Loto Taumafai's help to provide us with milk and pampers because we can't afford them”

“There is only 1 person in our family who is employed...we mostly depend on our families overseas to send us money to do our family obligations to the church and the village...the biggest struggle is the cost of her daily needs such as pampers and food to ensure that she maintains a healthy diet...but we can barely afford to cater for her needs sometimes as we also have to care and provide for our elderly grandmother...”

It is very often the physical barriers that society has not addressed in areas such as transport, information, communication, and workplace that may be the reasons why people with disabilities cannot be employed or reduces their chances to find suitable jobs, taking advantage of educational and training or commuting to facilities of all types.¹⁵⁵ The provision of access to appropriate and where necessary, specifically tailored forms of transportation or workplace is crucial in the realization by people with disabilities of the right to work and earn a living as required under Article 27.

Disability is closely linked to economic and social factors and “conditions of living in large parts of the world are so desperate that the provision of basic needs for all- food, water, shelter, health protection and education-must form the cornerstone of national programmes”.¹⁵⁶ Therefore, the State needs to provide more assistance to people with disabilities and their families and carers so that they meet their everyday basic needs. More support is needed for families so they do not have to rely solely

¹⁵³ See NPPD 2016-2020 at para 4.3.

¹⁵⁴ See NPPD 2016-2020 at para 4.3. Please note that these are unweighted results, so while they are indicative of the actual percentages in Samoa they are not completely representative. Samoa Disability Prevalence Report 2015, at pg. 13.

¹⁵⁵ See ICESCR Committee General Comment No.5 at para. 22.

¹⁵⁶ See *Ibid* 55 above at para 1.

on the traditional welfare net as, families, especially those with disabilities and those with financial incomes are unable to fully provide for the needs of people with disabilities let alone the needs of other family members. The *NPPD 2016-2020* provides that there needs to be established an economic support mechanism for people with disabilities, with a focus on direct programmes, mainstreaming within key sectors, and the advancing of inclusive frameworks and guidelines.¹⁵⁷ In relation to vocational training programmes and apprenticeship, this point has already been discussed under the Employment section of this report.

Government cannot simply continue to rely on NGOs and local and international donors for support. Having said that, families also need to play their part and prioritise family commitments in order to ensure that their relatives with disabilities receive adequate care and are able to have access to the necessary services. It is a general understanding that *fa'alavelave*, church obligations and social activities (such as bingo etc) can place a heavy cost and burden on families. When misunderstood or misused the importance of the cultural norms can unfortunately inhibit the ability of families to escape poverty. It is important that these cultural obligations are respected and valued, but at the same time they should take into consideration the needs of vulnerable families who cannot afford to uphold these obligations.¹⁵⁸

Recommendations:

- 18) Recommendation No. 33 of the first State of Human Rights Report 2015 is reiterated which provides that “Village councils and churches to consider alternative ways to minimise cultural and religious financial obligations, particularly for financially vulnerable community members”.¹⁵⁹**

8. Independent Living and Community Inclusion

Independent living refers to the human right of each person to make decisions that affect their lives and the respect that should be afforded to such decisions. This may include the right to make simple life choices about what to eat or drink, what clothes to wear, to much more important decisions such the right to vote or to sell property. Historically, people with disabilities have not been able to exercise this right as it was assumed that they did not have the capacity to make ‘sensible’ decisions in relation to such important areas of life.

8.1 Independent Living and Community Inclusion in the CRPD

Article 19 explicitly emphasises the right for people with disabilities to make choices that are equal to others. For instance, people with disabilities being given the opportunity to choose where and with whom they live and not be forced to live in a particular living arrangement against their will. It requires governments to provide in-home, residential and community support services to support families and carers who are caring for people with disabilities, so that people with disabilities can live independently and avoid being isolated in the community.

Article 12 protects people with disabilities’ right to independent living and inclusion in the community to ensure that people with disabilities enjoy the legal capacity to make decisions. *Legal capacity* has two elements: (i) *legal standing*, which is the ability to hold rights and to be recognised as a legal person before the law. For example being able to vote or owning a birth certificate, and (ii) *legal agency* which is the ability to exercise these rights and to have them recognised by the law.¹⁶⁰

¹⁵⁷ *See Ibid* 55 above at para.4.3.

¹⁵⁸ *See State of Human Rights Report 2015* at pg. 63.

¹⁵⁹ *See Ibid* at pg 63.

¹⁶⁰ Committee on CRPD General Comment No.1 ‘Article 12: Equality before the law’, at pg 3-4.

In order for people with disabilities to be able to exercise their legal agency, Article 12 requires the State to create an environment where they are able to make their own decisions, with the support of others if it is needed. If people with disabilities are unable to make their own decisions, then government needs to ensure that the “wills and preferences” of the person with disability are considered when someone makes a decision on behalf of person with disability.¹⁶¹ This principle requires the person who is making the decision to do so with respect to the “will and preference”¹⁶² of the person with disability.

8.2 Current Situation

As discussed earlier in the report, the *Fa’asamoa* can sometimes restrict a person’s right to make their own decisions, being overprotected by their families and/or carers. People with disabilities, especially people with intellectual disabilities, often have decisions made for them by other people (known as substitute decision-makers). These decision-makers are often medical practitioners, families and carers. While decision makers may be making decisions with the best interest of the person with disability in mind, they sometimes deny that person’s right to make their own decisions.

During consultation and focus group sessions, many people within the community felt that people with disabilities should be able to make decisions for themselves, but *only* if they are capable of doing so. If not, then the family or health professionals should make decisions for on their behalf. The Survey showed that 20% of participants without disabilities said that people with disabilities should not have the right to make their own decisions. This is opposed to the overwhelming majority of participants who had disabilities who indicated that they had complete control over all the decisions in their life. On the other hand, 15% of participants with a disability claimed not to have any control over decisions in their life. Furthermore, community consultations and results from the Survey show that people with disabilities do not have much support when making decisions.

Lack of Support Services

Unlike other countries, Samoa does not have the problem where people with disabilities are confined in institutions and segregated from their families. The Samoan family unit is the perfect structure to ensure that people with disabilities can live independently within their community. Assistance is also required to be provided to these families and carers of people with disabilities so that they are able to live independently in the community. However, during consultations, the Office received comments from families confirming that they do not receive any assistance from the government with regards to caring for family members who have disabilities. This sentiment is backed up by Survey which showed that around 56% of participants reported having struggled meeting their basic needs due to financial reasons. At the moment there is a lack of subsidised government services (such as health care services, medication, assistive devices etc) and no welfare support for people with disabilities and their families/carers. The support services that do exist are being provided by local and international NGOs, all of which rely on international funding.

Lack of Community Inclusion

Samoa society is group oriented. Families make up the wider community and communities make up the society we live in. Everyone does everything together within the community such as church activities and programs and various village activities. Despite this communal way of life, according to the community consultations and focus group discussions, it showed that not all people with

¹⁶¹ See *Ibid* at pg. 7-8.

¹⁶² If the will and preference of the person cannot be determined then the person making the decision should make their decision based on all the information available, including consultation family members and carers. If it is still not possible to determine what the person would likely want, then the person making the decision on behalf of the person with disability should try and uphold the person’s human rights and act in a way which is the least restrictive of the person’s human rights.

disabilities participate in this communal way of living. In general, most people with disabilities with physical impairments (but not people with intellectual disability) participate in village activities such as aumaga, aualuma, Women's groups (Komiti a Tina), Church (Youth) and some even hold matai titles. Although people with disabilities with physical impairments participate in these activities, they are not expected to make decisions or contribute to the decision making. In terms of people with disabilities who are intellectually impaired, they do not participate on the assumption that they cannot understand and make decisions. Therefore, there is a lack of full inclusion of people with disabilities in the communities.

"I try to go to village activities when I can but it makes me sad that I can't do much because of my condition"

Recommendations:

- 19) Government should increase support services for people with disabilities and their families such as the provision of free and affordable health care services and assistive devices.**
- 20) MWCSO in collaboration with NOLA and all community networks (e.g SN, STN, Youth, Church) should work to create a more inclusive environment by creating awareness about the rights of people with disabilities and increasing their participation within the village settings.**

9. Political Participation

Similar to the discussions in the previous section, the decision-making ability of people with disabilities, particularly those with intellectual impairment has always been limited due to their condition and they are underrepresented in political and public affairs.

9.1 Political Participation in the CRPD

Article 29 pushes for governments to guarantee for people with disabilities political rights and the opportunity to enjoy these rights on an equal basis with others. As such government obligations include:¹⁶³

- a) ensuring that people with disabilities can fully participate in political and public life including the right to vote and be elected to public office (either directly or through freely chosen representatives); and
- b) promoting an environment in which people with disabilities can fully participate or encourage their participation in public affairs.

9.2 Current Legal Framework

The *Electoral Act 1963*¹⁶⁴ stipulates that any person who is a Samoan citizen and who is 21 years old must register to vote. However, this does not include a person who is detained in accordance with the *MH Act*.¹⁶⁵ The Act further states that a person cannot become a candidate or be elected as a Member of Parliament if the person is of unsound mind and is subject to an order of medical custody issued

¹⁶³ The Convention on the Rights of People with Disabilities and Optional Protocol, United Nations, Article 29, at pg. 21-22.

¹⁶⁴ See Section 16 of the *Electoral Act 1963*.

¹⁶⁵ See Section 16 (5) (c) of the *Electoral Act 1963*.

under the *MH Act*.¹⁶⁶ Such requirements could be viewed as discriminating against people who have intellectual disabilities. Such restrictions may have been made because of the assumption that people with disabilities may not have the capacity to understand or comprehend their right to vote and what it represents; and it may be difficult to perform the duties if elected to Parliament.

9.3 Current Situation

In relation to the right to vote, the OEC in collaboration with NOLA and MWCSD conducted various community consultations and education to empower people with disabilities to realise the significance of exercising their obligation to register and their right to vote in the 2016 Election. Mobile registrations were also carried out around the country in efforts to address the issue of transportation for the public including people with disabilities. In recognising the need to further promote the right to vote for people with disabilities, OEC made special registrations around the country and provided transport (to and from the homes) of people with disabilities so that they can attend registrations. In addition, the number of special polling booths accessible for people with disabilities during the 2016 elections increased in comparison to previous elections. These special booths included the provision of a trained support staff to assist people with disabilities and elderly voters cast their votes.¹⁶⁷

The Office highly commends the collective efforts by the Government and civil society on the progress made to ensure the participation in political and public life for people with disabilities. However, more effort is needed to ensure that participation in political and public life for people with disabilities is realised in all levels of society including the family level and within political parties.

Lack of family support

Consultations with OEC highlighted that although the office provided a special registration and transport for people with disabilities, a low number of people with disabilities attended. This was because either the relatives were too busy to accompany them or the influence of negative attitudes within the family about the importance of including people with disabilities in decision-making process.¹⁶⁸ Hence efforts to support the empowerment of people with disabilities to participate in political process through voting must be accompanied by robust awareness raising programs targeting the family to ensure that such barriers of negative attitudes are fully removed as they significantly undermine their right to vote.

Lack of disaggregated data

The unavailability of accessible resources and information about voting reinforces barriers that affect the opportunity for people with disabilities to exercise their right to vote.¹⁶⁹ The OEC claimed this was a challenge in their preparation for the 2016 elections. Although financial constraints were one factor, the unavailability of data on the population of people with disabilities was a major concern. The availability of data on the total population of people with disabilities in the country who are eligible to register and vote which includes information on the types of impairment would better inform the work of OEC through the provision of accessible methods of information to cater for the needs of people with various impairments.

Furthermore, the State must ensure that necessary adjustments to the voting system and procedures are put in place. Such efforts must include ensuring facilities, transport and materials are accessible. Accessible information includes information on political parties, candidates and accessible voting forms for people with vision and intellectual impairments. It is the view of the Office that only through

¹⁶⁶ See Section 5 (5) (c) of the *Electoral Act 1963*.

¹⁶⁷ Office of the Electoral Commission consultations, 8 April 2016, on file at the Office of the Ombudsman.

¹⁶⁸ See *Ibid* 168 above.

¹⁶⁹ See *Ibid* 168 above.

the availability of meaningful data about the needs of people with disabilities and commitment by government to make available financial support to cater for these needs can the government guarantee a barrier free environment for people with disabilities to exercise their right to participate in the political arena by voting.

Continue support of participation

Government's obligation also is to actively promote an environment in which people with disabilities can effectively and fully participate in public affairs and are encouraged to participate on an equal basis with others.¹⁷⁰ NOLA, Samoa Blind People Association, SENESE and Special Olympics Samoa are some examples of organisations that promote and encourage an environment conducive to participation of people with disabilities in political, public and all other areas of life.

NOLA is the lead and governed by people with disabilities. It is well respected in the community and advocates for the voices of people with disabilities. It has been at the forefront of the movement to ratify the CRPD.¹⁷¹ In terms of empowering and encouraging its members to participate in public affairs,¹⁷² its Office Manager Ms Faatino Utumapu who has vision impairment often participates in the work of international organisations.¹⁷³ Special Olympics Samoa empowers and encourages participation of people with disabilities particularly people with intellectual impairments through sports. This organisation has opened doors for people with disabilities to represent Samoa in the international arena through the Special Olympics Samoa which is held every 4 years. However, like other disability organisations there is always a struggle to implement and achieve its community based programs and activities due to funding constraints.

The Office is concerned about the financial sustainability of disability organisations as they rely heavily on funding from overseas donors and local companies. It is the view of the Office that in line with government taking responsibility for the implementation of CRPD upon ratification, it must ensure that financial and resource support is given to disability organisations to secure operations while maintaining their independence as a NGOs. Through this partnership, government will promote an environment that encourages people with disabilities to participate in political, public and all other areas of life as per Article 29.¹⁷⁴

Recommendation:

- 21) OEC in collaboration with MWCSO and NOLA should increase their efforts to raise awareness within families with people with disabilities about the importance of people with disabilities' right to vote.**

10. Liberty and Access to Justice

People with a disabilities who are either victims or perpetrators of crimes usually rely on the justice system for protection, security and access to fair and equal treatment before the courts, tribunals, law enforcement officials, or prison systems. This is because they are more likely at risk of mistreatment and discrimination on the basis of their disability. A fundamental part of ensuring the enjoyment of rights for people with disabilities under the CRPD is the concept of access to justice, the respect of liberty and the security of the person. Access to justice for people with disabilities includes the

¹⁷⁰ See Article 29 of the CRPD.

¹⁷¹ NOLA consultations 20 March 2016, on file at the Office of the Ombudsman.

¹⁷² NOLA SDP Annual Report 2014-2015, at pg. 18-19.

¹⁷³ Included the representation of Samoa as part of the delegation in the 59th Session of the Commission on the Status of Women held in New York in March of 2015 and 2016.

¹⁷⁴ Pursuant to the preamble (m), (o), Art.33(3), Art.34(4) of the CRPD, the Government is required to provide support to the Disabled People's Organisation, which is NOLA

effective access to the systems, procedures, information, locations used in the administration of justice such as court houses, police stations etc. Where barriers exist to exercising these rights, they not only limit the ability of people with disabilities to use the justice system, but also discriminate against them on the basis of their disability.

10.1 Liberty and Access to Justice in the CRPD

Article 13 explicitly references the right of people with disabilities to access to justice. Article 14 specifically speaks to ensuring of liberty and security of people with disabilities. The article obligates Government to ensure that people with disability:

- a) are not deprived on their liberty unlawfully or arbitrarily;
- b) if they are deprived of their liberty through any processes, they are on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objective and the principles of CRPD, including by the provision of reasonable accommodation.

10.2 Current Situation

In consultations, representatives of the Ministry of Justice and Court Administration (“MJCA”) expressed the view that there are no overt barriers to people with disabilities because everyone is treated equally before the law.

They do not have formal policies and procedures in place to guide their work with people with disabilities at all levels of the justice process. Samoa’s Court House is partially accessible to some people with disabilities for instance ramps, rails, elevators as well as accessible court rooms for people who use wheelchairs. Furthermore, they provide a re-active approach when a matter involves a person with a disability. For example, if the person with a disability has a visual or hearing impairment, the Court makes arrangements for a translator and any other necessary assistance from SENESE or other relevant service providers. The Court registers and clerks also assist by reading the affidavits of the visually impaired as the Court currently does not have resources for Braille. However, in the Land and Titles Court, MJCA expressed strong concern that despite the sound system in place, a lot of older people with hearing impairments have difficulty in hearing and understanding the Court proceedings. To assist, the clerks are then asked by the judges to repeat statements to the parties. In doing this, some of the clerks feel that receiving and referring evidence/information to the judge and parties, the process is not done properly. In consultation with the Samoa Law Society, the President said that there has not been any issues in representing people with disabilities. They work closely with Court to ensure that the appropriate services are provided for the people with disabilities.

It is clear that there are some procedures or processes in place. However it is important that the Ministry exercising justice has in place formal procedures and policies in order to fully facilitate the participation of people with disabilities in all legal proceedings as per Article 13. Government must also ensure effective access to justice for people with disabilities by promoting appropriate training for those working in the field in administering justice such as police and prison officers. A collective effort by MJCA and NOLA to ensure targeted trainings is carried out in order that people with disability receive the services and access to justice on the equal basis with others and without discrimination on the basis of their disability.

It is also assumed that there is a generic process within the MOP in dealing with people with disability¹⁷⁵ in relation to filing a complaint, a person who has been charged, etc. On the other hand, in consultations with the SCPS, the Office was informed that they have no existing formal policies to guide their work with people with disabilities. However they do recognise the needs of people with disabilities and SPCS endeavours to provide support where needed and necessary. Although current facilities do not cater for the needs of the people with disabilities, SPCS has provided some form of

¹⁷⁵ It was not possible to obtain the policies and processes despite numerous attempts to set up consultations with MOP.

accommodation such as a brief medical check for all prisoners prior to entering Tafaigata, an aide for a blind prisoner or house them in an open house for ease of movement. From these medical checks, it reveals some prisoners have intellectual impairment. Currently, there is one person with a physical impairment in prison and SPCS does its best to include him in all development and rehabilitation programs. It is hoped that the new facilities currently in the pipeline will cater for the needs of people with disabilities.

Recommendations:

- 22) MOP and MJCA should mainstream all their policies so they are disability inclusive and ensure that people with disability have equal access to justice.**
- 23) SPCS should ensure that the new prisons should be compliant with the CRPD including access to and around the building and rehabilitation programs.**

PART V: ECONOMIC ANALYSIS

It has been well established that there are links between the full and equal participation of people with disabilities in society and sustained economic growth. All human rights are ‘universal, indivisible and interdependent and interrelated. It is evident from the findings of this report that there are a range of barriers in Samoa which prevent people with disabilities from gaining an education, from obtaining a job and therefore not being able to contribute to the economy.

“The extensive exclusion of people with disabilities from society is indefensible from a human rights and social justice perspective. However, while this may be widely acknowledged, there is a common perception that inclusive interventions are not financially feasible particularly in the resource-constrained settings of many low and middle income countries (LMICs).

Although the human rights case alone is sufficient to necessitate action, there is also evidence that promoting inclusion of people with disabilities is beneficial from an economic standpoint. Some individual studies have estimated the costs of exclusion and potential gains from inclusion in areas such as work or education, however a comprehensive economics-based argument has not been extensively detailed.”¹⁷⁶

From a human rights and social justice perspective, the widespread exclusion of people with disabilities from society is unequivocally unacceptable. The evidence presented in this report, emphasises that exclusion is also untenable from an economic perspective: not only does exclusion create a significant economic burden for individuals and their families, but it can also carry substantial costs to societies at large.

Assessing ratification and implementation costs in the case of the CRPD can be a useful exercise as it can ‘help understand the direct costs of disability and help policymakers better identify the specific needs of people with disabilities and their households’.¹⁷⁷ The Costed Implementation Plan undertaken by the Government is a commendable effort in ensuring solid financial planning for implementation of CRPD is in place before ratification occurs. However, it did not sufficiently consider the costs of disability in Samoa and was lacking in its consultation with people of disability themselves. It is timely at this stage to remind ourselves of the phrase ‘nothing about us without us’ and that people with disability must be at the centre of all ratification and implementation plans.

Whilst a costed implementation plan can be helpful in terms of financial planning it should not be the deciding factor when the Government is considering the ratification of the CRPD. Further, the cost should not be a barrier to the ratification of the CRPD. Rather the Office reminds the Government that ratifying the CRPD will bring economic and social benefits to the community and these benefits should be the main focus of ratifying the CRPD.

This chapter therefore considers the three main economic considerations in ratifying CRPD:

- a) **Government Spending**
- b) **Economic empowerment of people with disabilities; and**
- c) **Economic empowerment of families of people with disabilities.**

¹⁷⁶ The Economic Costs of Exclusion and Gains of Inclusion of People with Disabilities: Evidence from Low and Middle Income Countries, Lena Morgon Banks and Sarah Polack, International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine, at pg i.

¹⁷⁷ Review of the Economic Costs of Exclusion of People with Disabilities in Asia and the Pacific’, United nations ESCAP and Social Development Division (December 2015).

a. Government Spending

In terms of Government spending, the Costed Implementation Plan ensures the solid financial planning for implementation of the CRPD is in place before ratification has occurred. The Office also believes that any perceived financial constraints with regards to ratifying CRPD, can be overcome with the support of the international community. Financial obligations should therefore never be considered a hurdle that cannot be overcome when it comes to ratifying and implementing human rights treaties.

b. Economic Empowerment of People with Disabilities

There is a strong argument when it comes to the economic benefit which results from the empowerment of people with disabilities and their families. A United Nations Paper on the Economic Costs of Exclusion of People with Disabilities in Asia and the Pacific (December 2015) found the direct economic impact of excluding people with disabilities from employment leads to losses of up to 7% of a country's gross domestic product.¹⁷⁸ This rate could be far higher if indirect losses are also taken into account such as reduced levels of access to education and the economic impact on arising as a result of family members working fewer hours to care for a person with a disability.¹⁷⁹

Case Study: Faaolo Utumapu-Utailesolo – Empowering people with disability

Faaolo is a female who is 39 years-old. She is from the villages of Safotu, Vailoa Palauli, and Vaitele-Uta. She was born with vision impairment. Despite her visual impairment, her parents put her in school. Her parents who were both teachers instilled in her the value of education no matter her disability. They made her go to school even if three quarters of the time she refused to. When she was four years old, she was taught at home by visiting teachers for the blind of how to read braille and write. It was challenging and she hated it in the beginning but she now appreciates its value.

She did not have trouble in accessing the school buildings but she had difficulty with the school materials as there were no textbooks in Braille for her. She relied on the handouts in Braille from the organisation called PREB which is now known as the Samoa Blind Association. She also relied on the notes dictated by my classmates and teachers which she typed on her noisy Braille machine. She later went on to universities in New Zealand and Australia to complete her Bachelors and Masters.

Finding a job after attaining her qualifications was another challenge. It was hard for people with disabilities to get a job. She found that there were two types of employers, the ones who give you a chance and the ones who count you out when they hear the word "blind" no matter how many qualifications you have. She found that no matter what, one had to still prove themselves and work harder than anyone else to maintain that standard. It's not just your reputation as an employee with a disability that is on the line, it's trying to secure any opportunities for others with disabilities.

“I have lost count of job vacancies I have applied for and got declined. But that is ok because only the exceptionally smart employers will give me a chance because they know I can be exceptional at what I do”

¹⁷⁸ Review of the Economic Costs of Exclusion of People with Disabilities in Asia and the Pacific', United Nations ESCAP and Social Development Division (December 2015).

¹⁷⁹ See *Ibid* 179 above.

She has since been employed in five (5) workplaces in Samoa. She currently works with SENESE Inclusive Support Services as Promotion and Awareness Coordinator. She contributes to supporting her nuclear and extended family financially.

She has a family and the biggest highlight of her life was having her son. He is three (3) years old. She has help from her husband, her family and friends looking after him. She has dispel the myth that women with disabilities cannot raise children and have families. She believes that that is a total misconception.

She holds various roles in the Community as the choir master in the Vaitele-Uta Methodist Church, President of the Samoa Blind Persons Association, Secretary of the Board of the Nuanua o le Alofa and a Board Member of the Pacific Disability Forum.

c. Economic Empowerment of Families of People with Disabilities

There is a growing body of research to show that the opposite – exclusion – leads to strong links between disability and poverty.¹⁸⁰

Generally families' with at least one person with a disability incur extra living costs in comparison to a family that does not include a person with a disability. The exact level of additional expenses¹⁸¹ incurred by people with disabilities and their families in Samoa is unknown due to the lack of available data but other research suggests that this could be as high as 40% of all income for those with a moderate disability and up to 70% for those with a severe disability.¹⁸²

The United National Economic and Social Commission for Asia and the Pacific report concludes, “societies can mitigate these costs by addressing the nexus between disability, lack of employment and poverty through inclusive development so as to break down the barriers faced by people with disabilities in terms of obtaining an education, finding employment, and, by and large, participating in their communities.”¹⁸³ The answer to addressing this poverty trap is twofold; first to ensure full and active participation of people with disabilities wherever possible and secondly to introduce social protection for those who are unable to fully participate. Additionally, to ensure the full economic empowerment of people with disabilities and their families the following steps must be taken:

- a) The Government should establish programs and assistance that meets all of the hidden costs of living with a disability, from covering the cost of mobility devices to subsidising public transport;
- b) The Government should explore a means tested social benefit scheme for people with disabilities who are unable to enter the workforce despite all reasonable efforts to remove barriers, thus economically empowering their family.

The final point to make in this brief economic analysis is to draw the link between human rights and development, which is not always fully understood or appreciated. Whilst this link has been explored in some detail above, demonstrating how inclusiveness of people with disability can lead to a more economically prosperous society the link runs far deeper.

¹⁸⁰ Tarque et al (2014); Mitra et al (2013); Trani and Loeb (2012); WHO/World Bank (2011); Groce et al (2011); Mont and Cuong (2011); Braithwaite and Mont (2005).

¹⁸¹ These additional costs could include required assistance devices, increased public transport costs, rehabilitation services, personal assistance, medical services and more. Furthermore, it has been shown that in families with a person with a disability any children are less likely to attend school due to the additional caregiving and work responsibilities that exist, thereby reducing future income for that family through more limited opportunities.

¹⁸² Review of the Economic Costs of Exclusion of People with Disabilities in Asia and the Pacific', United nations ESCAP and Social Development Division (December 2015) at pg.21.

¹⁸³ See *Ibid* 183 above.

The United Nations Development Program observed that “a decent standard of living, adequate nutrition, health care, education and decent work and protection against calamities are not just development goals – they are also human rights”.¹⁸⁴ There are over 300 linkages between the rights contained within CRPD and the Sustainable Development Goals. Full implementation of the CRPD will therefore also help Samoa play its part in achieving the SDGs and work towards a more sustainable future, nationally and globally, where each and every person enjoys equal opportunities irrespective of disability in the mutual interests of each and every one of us and in the full spirit of the *Fa’asamoa*.

¹⁸⁴ UNDP, ‘Human Development Report’ (2000).

PART VI: TABLE OF RECOMMENDATIONS

Recommendation	Section of the Report	Responsible Party	Timeframe (to action recommendation)
1) The Government should develop an Action Plan in order to co-fund the SDP 2013-2017 with the aim to completely fund the SDP 2013-2017 upon its completion.	Analysis	Government	Initiate discussions before the completion of the SDP 2013-2017
2) OAG, MWCSO and SLRC should complete the LCR and ensure that it fully harmonises all of Samoa’s laws with the CRPD.	Equality and Non-Discrimination	OAG, SLRC, MWCSO	Before ratification of the CRPD
3) The MOP should develop clear guidelines for reporting abuse and sexual exploitation of women with disabilities. These guidelines should be gender, age and disability sensitive.		MOP	Immediate
4) Government should consider the following to ensure accessibility for people with disabilities: a) adopt an action plan that identify existing barriers to accessibility; b) ensure such action plans are strictly implemented; c) set time frames with specific deadlines; d) provide the human and material resources necessary to remove these barriers; e) strengthen their monitoring and regulatory framework to ensure accessibility; f) provide CRPD training and capacity building for staff that are responsible for the monitoring of these standards.	Accessibility and Mobility	Transport Sector	Progressive
5) The NHS and MOH, in collaboration with NOLA, should carry out awareness activities to ensure that people with physical disabilities and families/careers are aware of the benefits of the mobility devices and the services that are available at MDS.		Health Sector, NOLA	Immediate

6) NOLA in collaboration with MESC should ensure that all schools are covered in the awareness programs that targets children and teachers.		Education Sector, Community Sector, Disability Sector	Immediate
7) NOLA in collaboration with MWCSO and the community networks (e.g STN, SN, Youth and Church) should increase their efforts in raising awareness within the family unit about the rights of persons with disabilities.	Awareness-raising	Education Sector, Community Sector, Disability Sector	Immediate
8) MCIL, PSC, MWCSO, in collaboration with NOLA and Chamber of Commerce should carry out more awareness raising activities to promote the capabilities of people with disabilities in the employment sector and the contribution they can make in the development of their communities.		MCIL, PSC, MWCSO, NOLA, Chamber of Commerce	Immediate
9) The NHS and MOH should ensure that people with disabilities have access to free or affordable health care in Samoa via the implementation of a subsidy card for people with disabilities.		Health Sector	Within a year from ratification of CRPD
10) The NHS and MOH should collaborate to develop a strategic plan to increase allied health services and undertake awareness raising activities in schools promoting the roles of allied health professionals.	Health	Health Sector	Within a year from ratification of CRPD
11) The NHS should consult with the OAG about how the <i>MH Act</i> should be amended so that it is compliant with the CRPD.		NHS, OAG	Before ratification of CRPD
12) The Government should provide funding to the Goshen Trust so that the can adequately provide services for people with acute psychosocial disabilities.		MOF, NHS, MOH	Initiate discussions for the provision of budget in the next financial year (2017- 2018)

<p>13) MESC should prioritise the preparation of an Action Plan of how to achieve the IEPSLD including:</p> <ul style="list-style-type: none"> a) set realistic timeframes; b) identify the budget, c) how to raise the capacity of the personnel (ie: the current teachers, teacher aides, student teachers), d) reasonable accommodation through the universal design of educational facilities; e) support measures (such as the appropriate curriculum, assessment and test criteria, teaching in the appropriate method through Braille, electronic readers, sign language). 	<p>Education Sector</p> <p>Education</p>	<p>Initiate discussion immediately and implement within year from ratification of CRPD</p>
<p>14) MESC should work in collaboration with NUS to develop the current inclusive education course into a full program, and provide initiatives to encourage students to undertake this profession.</p>	<p>Education Sector</p>	<p>Initiate discussion immediately and implement within year from ratification of CRPD</p>
<p>15) MESC should activate and strengthen the Inclusive Education Unit within MESC to implement the IEPSLD in coordinating with the service providers.</p>	<p>Education Sector</p>	<p>Immediate</p>
<p>16) MCIL and PSC in collaboration with SBS should carry out an extensive survey to obtain disaggregated data on the number of people with disabilities who are employed to ensure their needs are catered for.</p>	<p>MCIL, SBS</p>	<p>Initiate discussion immediately and implement within year from ratification of CRPD</p>
<p>17) Government should improve its efforts in creating job opportunities for people with disabilities through awareness within the public and private sector focusing on the benefits of employing of people with disabilities.</p>	<p>Employment</p> <p>MCIL, PSC</p>	<p>Immediate</p>
<p>18) Recommendation No. 33 of the first State of Human Rights Report 2015 is reiterated which provides that “Village councils and</p>	<p>Community</p>	<p>Immediate</p>

churches to consider alternative ways to minimise cultural and religious financial obligations, particularly for financially vulnerable community members”.

Adequate Standard of Living and Social Protection

<p>19) Government should increase support services for people with disabilities and their families such as the provision of free and affordable health care services and assistive devices.</p>		<p>Government</p>	<p>Initiate discussions after ratification of CRPD</p>
<p>20) MWCSO in collaboration with NOLA and all community networks (e.g SN, STN, Youth, Church) should work to create a more inclusive environment by creating awareness about the rights of people with disabilities and increasing their participation within the village settings.</p>	<p>Independent Living and Community Inclusion</p>	<p>MWCSO, NOLA, Community</p>	<p>Immediate</p>
<p>21) OEC in collaboration with MWCSO and NOLA should increase their efforts to raise awareness within families with people with disabilities about the importance of people with disabilities’ right to vote.</p>	<p>Political Participation</p>	<p>OEC, MWCSO, NOLA</p>	<p>Immediate</p>
<p>22) MOP and MJCA should mainstream all their policies so they are disability inclusive and ensure that people with disability have equal access to justice.</p>		<p>MOP, MJCA</p>	<p>Immediate</p>
<p>23) SPCS should ensure that the new prisons should be compliant with the CRPD including access to and around the building and rehabilitation programs.</p>	<p>Liberty and Access to Justice</p>	<p>SPCS</p>	<p>Progressive</p>

ACKNOWLEDGEMENT

It is important to recognize the assistance, contribution and support of various NGOs, Government Ministries across the Disability Sector, development partners, schools and the whole community in putting together this report.

Thank you to Loto Taumafai, Special Olympics, Goshen Trust and Nuanua o le Alofa for acknowledging this work and their collaboration. Your partnership made it possible to reach out to some of our people with disabilities and ensure that their voices echo in this report.

Thank you to various Government Ministries, organisations and development partners¹⁸⁵ for time taken for input, review and provision of comments and providing substantial information, data and consultation support towards this report.

Thank you to all the listed villages¹⁸⁶ who participated in the consultations, focus groups and the survey. You made time to attend and participate in the Survey and provided valuable thoughts and experiences during the focus group discussions.

A special thank you to the MWCSO for facilitating arrangements with villages for consultations, *STNs*, *Sui Tupulaga Talavou* and *SNs*, networks for participating and carrying out your duties to ensure that dates and venue for consultations and villagers were notified and confirmed.

Thank you to the Principals and students of all the schools¹⁸⁷ who participated and shared their thoughts in the Survey. The qualitative responses the Office received were astonishing and invaluable.

The Office expresses its appreciation to its Advisory Council for their contribution and support (especially Tavui Annie Laumea and Tafilelea Fifita Tanielu for participating in the village consultations) and Lufilufi Taulealo for translating the report.

Finally, distinct gratitude and appreciation towards the people with disabilities and their families who we visited for giving your time to be interviewed and allowing case studies on your lives and the lives of your loved ones with disabilities to paint a picture of the challenges and success for people with disabilities living in Samoa for the purpose of this report.

¹⁸⁵ See Annex A for list of all Government Ministries and organisations involved in the report

¹⁸⁶ See Annex A for list of all Villages and groups involved in the report.

¹⁸⁷ See Annex A for the list of all Schools involved in the report.

ANNEXURE