Autism as a Blessing in Disguise: Towards an EFKS Ministry of Hope amidst the Challenges of Autism Spectrum Disorder (ASD)

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Aunese Anau

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Declaration of Authorship

I, Aunese Anau,

hereby declare that this submission is my own work and that, to the best of my knowledge, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma at Malua Theological College or any other educational institution, except where due acknowledgement is made in this thesis. Any contribution made to this research by fellow students and staff at Malua Theological College or elsewhere during my candidature is fully acknowledged.

Signature: Date: 08 November 2021

Abstract

Writing this thesis has been a privilege and an opportunity to promote and raise the level of awareness for Autism Spectrum Disorder within the EFKS. Our experiences raising our children with Autism (ASD), has opened our eyes to embrace the beautiful world of ASD. Although ASD encompasses many challenges for us as parents (to children with ASD), it is ever more so challenging for our children with ASD. Hence, the aim of this thesis is to develop a resourceful guide, for parents with Autistic children within the EFKS. Our faith and love in God has encouraged us to keep moving forward to overcome the many obstacles we encountered pre diagnosis and post diagnosis of ASD. The dynamics and multidimensional realm of hope has helped us cope through it all. It all starts within the family circle (immediate family) to acknowledge, accept and be aware of ASD. When the family circle can achieve this, then we will be able to contribute effectively towards the development of our children living with ASD in everyday life. Through love and understanding of our children living with ASD, we can illuminate their hopes (our children with ASD) and our hopes (as parents) that they are our blessings in disguise.

"My dear sweet child, I hope you know that I am doing the very best I can. There are days that I do not understand what you need. Some days, my patience wears thin. Many days my heart breaks seeing you struggle; but there is not a single day that goes by that I am not the proudest parent ever. You are my life, my purpose, and the love I feel for you is never-ending. Autism can be hard, but loving you is easy."[1]

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[1] Temple Grandin, *The Way I See It : A Personal Look at Autism & Asperger's*(Arlington, TX: Future Horizons Inc., 2008)., p. 56

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Dedication

This thesis is lovingly dedicated to our beloved parents: The Late Aunese Anau Snr and Foga'a, Tariu Faiilalo and Nofo for leading us to God. We are forever grateful. *"Mum and Dad, I know that you both are not here to read this, but I sure hope that I have made you both proud. I love you both and the memories of you will remain in my heart forever".*

To our siblings for all of the sacrifices on our behalf. Our highest gratitude.

To my wife Fiona Anau. Words cannot do justice to your endless love and support. In times when I felt like giving up, you never once waived. I am never complete without you. Thank you for always believing in me.

Finally, to our dearest children: Muzyc, Darius, Samson, Iahessedene and Etiveni-Maluapapa Anau. I cannot thank God enough for blessing us, for each and every one of you. You have all made mummy and daddy's life so much more meaningful. This thesis beats with your hearts. The true inspiration and reason why I have written this work. Thank you for letting mummy and daddy experience your unique world. We love you all immeasurably.

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List of Figures and Illustrations

List of Abbreviations

ASD	Autism Spectrum Disorder
EFKS	Ekalesia Fa’apotopotoga Kerisiano i Samoa
PWD	People with Disabilities

Glossary

EFKS	Congregational Christian Church in Samoa
Fa'aaloalo	Respect
Fa'asamoa	Samoan
Fa'aekalesia	Ordination to partake in the sacrament of the Eucharist
Faifeau	Reverend/minister/church leader
Faigataulaga	Offering
Falesa	Church building/place of worship
Feagaiga	Covenant
Ma'i	Sickness and or someone with special needs
Ma'iaitu	Possession by a spiritual being and or spiritual sickness
Ōtisi	transliteration of the term Autism
Tagata lotu	church members
Ulavale	Naughty

Chapter One

Introduction

1.1 An Introduction

Autism has no cure, but it does not mean it cannot be improved. Muzyc, our Autistic daughter was referred to an early intervention programme which offered ongoing speech and occupational therapy and ongoing psychologist (Autism specialised) consultation. During this programme, Muzyc propelled through the basics of learning how to be patient, share, to be calm and happily spoke her first word “dad”. These are some of the major changes we experienced in the first month of her participating with the ongoing programme.

Paediatrician specialists (in diagnosing Autism) highlight the need for parents to screen their children (that are suspected of Autism Spectrum Disorder) at an early age. Research has proven the level of improvement for children with Autism in terms of social behaviour and a consensus about crucial aspects such as intensity, family involvement and focus on generalization. Therefore, early diagnosis of Autism should be promoted to allow early intervention programs, as it is critical towards development of a loved one living with ASD.[2]

Without faith, there is no hope, and without hope there is no true faith. Prince Clarence in his book titled “There is Hope! Keep the Faith” [3] reflects upon the basic Christian principles as he exemplifies the inseparable connection between faith and hope. Jurgen Moltmann perfectly gives a theological perspective and his theory regarding the connection

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[2] Christina Corsello, "Early Intervention in Autism," *Infants & Young Children* 18(2005)., p.82-112

[3] Prince Clarence, *There Is Hope! Keep the Faith!*(Authorhouse2008)., p.67

of eschatology and its role in the formation of living hope for Christians in his book called "Theology of Hope"[4]**.** The eschatology referred to by Moltmann is end of all things in history. The return of Jesus Christ, the coming of the judgement of God upon the whole world and the restoration of all things to a new creation. There is no part of the Christian faith that is not infused with this eschatological emphasis. The passion of longing for the coming of God. The goal is not to think about hope, but to think out of hope. Hope in what is to be accomplished and promised, as a starting point rather than the end of Christian theology. With this perspective Moltmann says, that because we hope for the Kingdom of God, we act to transform the world. Now because we believe that the transformation of all things is coming in God's coming, we know that the struggle for justice will be victorious. Therefore, we have the courage to face our struggles of today with the hope and knowledge that God is also struggling and suffering together with us.[5]

As members of the EFKS church and parents to two Autistic children, Jurgen Moltmann perfectly defines our quest for hope. A hope through the struggles and challenges we had to endure and overcome raising two Autistic children. Specifically, regarding their improvement in development and progress living with Autism (more specifically with Muzyc). Moltmann's perspective about hope creates an understanding of the sure hope that God has in store for the whole world, through the suffering and the resurrection of Jesus Christ. Moltmann seems to recount our thoughts and feelings in the beginning of when we first encountered ASD. Moltmann says that because we are confident that God will fulfill all His promises to the world through Jesus Christ, we are also confident that God will be present in everything we face in this world. That is why there is no end to hope but the effort

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[4] Jurgen Moltmann, *Theology of Hope* (Tottenham Road, London SCM Press Ltd, 1967)., p.11

[5] Jurgen Moltmann, Theology of Hope (Tottenham Road, London SCM Press Ltd, 1967)., p.67-79

to move forward striving for a better outcome in the future. Through faith we believe that God is with us not only in times of prosperity but also in times of adversity.

The implication is to look for another way to do things. It is because of hope; we strive to be better in life. As Muzyc's parents, it was hope and love that motivated us to do everything that we could do, to help give Muzyc the best chance of enjoying life to the fullest. Hope in our faith, to educate us further into understanding our purpose and obligation as parents to Autistic children. Moltmann says that because of the hope, a Christian ignores the problems of this world because Jesus Christ also suffered. If Jesus Christ has resurrected from death, so as we would be victorious over the struggles of life. Autism can be difficult for some couples and families. However, hope and our love for our children with ASD is the founding key to nurture, learn and understand the norms of an Autistic individual.

1.2 The Aim of this study

The aim of this study is to develop a useful guide for parents with Autistic children within the EFKS. The hope is to have ASD children participate in events and worship services of the EFKS. Inclusions in church events aim to develop a ministry of hope in the EFKS for Autistic children and their family members. It is important that ASD in the EFKS is documented and studied, for this will be a contribution to raising awareness about ASD, by articulating my experiences of being a father to two Autistic children. This will include taking a practical approach in the methods of communicating with Autistic individuals. For example, Buddy System Framework[6] approaches, in response to deal with ASD.

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[6] Buddy System Framework = practice that creates a stable between two individuals or known as buddies. Operate as a single unit to monitor and support each other.

Hope is the mechanics of this paper, but love is the spirit of this paper; because as hope is so many sided, love is also multifaceted, meaning hope is love. This paper includes our personal experiences in dealing with our two ASD children. We hope that our personal experiences and knowledge about ASD can assist members within the EFKS church. Utilizing the EFKS as a platform to educate and pave the way towards raising awareness for ASD.

1.3 Research Question

The central research question that will drive this thesis is as follows: How will knowledge and understanding of ASD develop a ministry of hope for EFKS inclusive of Autistic Children? Supporting questions that will assist the above primary question are as follow:

i. How can one differentiate between *ulavale* and ASD?

ii. What is the level of awareness about ASD in the EFKS churches?

iii. What are some of the problems of dealing with Autism within the EFKS?

1.4 Methodology

This thesis uses a Mixed-Methods methodology. Primary text will be the consulting of books, journal articles, and documentaries on autism in Samoa and abroad. Interviews will be conducted with church leaders in Samoa and overseas as well as various members *tagata lotu*. Articulated questionnaires to church ministers, *tagata lotu*, youth will also be used to establish a wider aspect and view of ASD. I also plan to visit one of the schools in Samoa who have individuals with autism, to conduct interviews with staff members and the families of the individuals that attend this school.

1.5 Chapters Outline

Chapter One is an introduction to this study.

Chapter Two includes a review of literature about ASD. Definitions of ASD will also be given. A general understanding of the term *ulavale* and its difference to ASD is presented. This chapter also presents a case study from a personal account.

Chapter Three includes the involvement of the church, extending the family circle to the EFKS. The findings, presenting an understanding of ASD from the data collected. This chapter outlines proposed understandings of ASD from the perspective of EFKS church members selected to participate in this research. This chapter will also reflect upon salvation and ASD.

Chapter Four proposes A Way to help, including a practical proposal to help approach interactively to ASD: The buddy system framework an on-going psychological and therapy training to be acknowledged, accepted, and understood. The contribution of the EFKS on Autism and how they can help will also be discussed.

Chapter Five as the Conclusion sums up the entire work. Offering words of encouragement to the members of the EFKS church in relation to raising awareness about ASD, and how to work with individuals diagnosed with ASD. I propose the need to raise awareness to the communities in Samoa and for Samoans abroad about the challenges of living with a person with ASD; thus, developing the ministry of hope within the context of the EFKS.

Chapter Two

Literature Review

2.1 Background to Autism Spectrum Disorder

Autism has been ongoing research since 1906. Autism first appeared in 1908. Eugen Bleuler used this term to describe a schizophrenic[7] patient who had withdrawn into a self-aloofness. Autism is Greek for **αὐτός** (autos) meaning self at first means, morbid self-admiration, and withdrawal within self.[8] An ASD individual is viewed being in their own world, without any acknowledgement to their environment and the people around them. In 1940, a child psychiatrist Leo Kanner in 1943 and pediatrician Hans Asperger in 1944 conducted collaborative studies. They discovered the realisation of the skills of an Autistic child, lacking in one area, but advancing in another. Coincidently, researchers were committed to the cause of Autism. This was unsuccessful as to various conclusions, such as bad parenting or pointing to disturbance in the early development stage of the child. In the 1980's, research on Autism gained momentum. It pinpointed that causation was a neurological and genetic ailment, and not bad parenting. Autism is a permanent disorder. Many countries are aware of Autism, via a study response towards an education research basic intervention skill. Samoa has no term for Autism, but I propose *Ōtisi* as a Samoan transliteration. Little is documented about *Ōtisi* in the EFKS. This thesis will work to address this issue.

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[7] Schizophrenia/Schizophrenic = Chronic brain disorder. Symptoms include hallucinations, disorganized speech, trouble with thinking and lack of motivation.

[8] Jerome Blake, H Eugene Hoyme, and Patricia L Crotwell, "A Brief History of Autism, the Autism/Vaccine Hypothesis and a Review of the Genetic Basis of Autism Spectrum Disorders," *South Dakota Medicine* (2013)., p.32-47

2.2 Definitions

Autism Spectrum Disorder (ASD) is a developmental disorder that affects communication and behaviour.[9] Assessment depends on age and time. Symptoms appear in the second or third years of life. During these ages, a child may not achieve the usual milestones expected, and causes parents to be anxious. Signs and symptoms of Autism varies. Depending on the level of Autism and diagnosis of each person, there are three categories of ASD.

2.2.1 Autism Disorder

Autism Disorder are individuals that struggle with verbal and non-verbal communication, due to relapse in speech. This leads to constant facial expressions and avoiding eye contact when speaking. All five senses become heightened. Their world is a constant with little or no change. Certain words designate a specific activity or norm, until such a time a new word/activity is introduced. This undertaking is at times difficult, as it may invoke a severe adverse reaction in the child, due to the change in routine or constant. A person with ASD lacks social skills. Individuals find it challenging to communicate with other people. This is due to the underdeveloped emotions and feelings that they express it.

2.2.2 Asperger Syndrome

Asperger Syndrome is a mild level of Autism Disorder. Here, individuals find it hard to express their feelings socially and are labelled as rude, unsympathetic even selfish. Persons with Asperger Syndrome struggle non-verbally, which could result in an inappropriate way of using body language, gesture, and facial expressions.

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[9] Autism Speaks, "What Is Autism." https://www.autismspeaks.org/what-autism retrieved 16/04/2021

2.2.3 Pervasive Development Disorder

Pervasive Development Disorder is an observation of someone's behaviour that is expected to be Autistic despite not being assessed or medically diagnosed ASD. Autism is a lifelong disorder, and it has no cure; however, treatments and services can improve a person's symptoms and ability to function. The hope promised in the Christian society is highlighted in Moltmann's book Theology of Hope[10]. The essence of this paper is to promote a life of hope sure hope, not only on the level of life satisfaction, but reflecting the spiritual satisfaction as EFKS members for dealing with a child with ASD. I hope to encourage and provide a sense of hope. The initial assumption of an ASD diagnosis is met with the insurmountable challenges culminating a wrong attitude. It is not just a proposition to achieve the goals in life, but a determination to engage with anticipation to achieve a progressive development for their loved ones with ASD, and their families.

Moltmann says that because we are confident that God will fulfill all His promises to the world through Jesus Christ, we are also confident that God will be present in everything we face in this world; an endless hope. Thus, we will always see a better outcome in the future. It is also the assurance of a life of faith. Reassuring that God is with us, in times of prosperity and adversity. Introducing ASD into our family has not been easy. Doctors ascribe the symptoms as stressful and seemingly hopeless, not only for us, but also for the future of our daughter. Although hope seemed to fade, but we are faithful believers in God, thus the hope of striving for something better has never ceased.

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[10] Moltmann, *Theology of Hope* ., p. 24 - 37

Autism Speaks[11] is an online resource used to promote ASD and present a fair understanding about ASD. There is a wealth of information and research on ASD offering definitions of ASD. There is no Samoan term for ASD according to SENESE a school in Samoa offering inclusive education for different abled children *(‘aoga mo ē o lo’o i ai manaoga fa’apitoa).* I propose the term *Ōtisi* as a Samoan transliteral translation of the term Autism. The need to have a Samoan term for Autism is purely an aural association of our community of the term Autism. However, in my view, this definition would only give a basic understanding expected from an individual with ASD. Throughout this thesis, the reader will come to learn that there is more to ASD, than the debilitating view of the public that they are usual portrayed as.

James E Johnson emphasizes on the word play[12] This selection of this book demonstrates the mindset of an ASD child in relation to the Samoan term *ulavale*. When a child engages in the activity of ‘play’, it should be depicted as the child’s way of communicating, social inte-racting and expression. In this thesis, I refer to my personal experience in the context of church. When in worship, our children with ASD engage in plays making noises and running around. Numerous times, children with ASD would be labelled as *ulavale*. In actual fact, it is the child’s (with ASD) way of communicating and expressing themselves. Over time we taught our children when and where to engage in the activity of play. We use visuals and body language to communicate to our ASD children.

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[11] Autism Speaks, https://www.autismspeaks.org › what-autism (2005)., retrieved 16/04/2021

[12] James E Johnson et al., *Play and Early Childhood Development* (Scott, Foresman & Co, 1987).,p.14-23

Janet Pereira's journal focuses upon raising children through obedience, from a Samoan perspective.[13] I have referenced this journal for the purpose of providing a definition for the word '*ulavale'* in two words '*ula'* and '*vale'*. *'Ulavale'* as defined by Pereira as associated with describing behaviour as naughty. I argue in my thesis that the word '*ulavale'* can be interpreted and used to pass judgement about an ASD individual's behaviour. ASD individuals on many occassions are labeled '*ulavale'*, based on perception, without further investigation.

The concept of *fa'aaloalo* by Kupa,[14] reflects the behaviour of a person to another within communal gatherings, in the context of the EFKS. Samoans religiousness of attending church every Sunday is essential to spiritual growth and blessings. The *falesa (*church) is a place to worship God in a respectful manner. However, a child being *ulavale* would be problematic for parishioners and church leaders conducting service. What about children/people with ASD? It is fair to acknowledge that the word *ulavale* is not only a broad and frail statement, but also a judgement given reflecting stigma. Labelling every child that does not meet the requirements influenced by a cultural perspective, while in the process of worshiping God.

Furthermore, the concept of *fa'aaloalo (respect)* to explain the cultural logic of Samoans and religion, includes the revolution of the term *feagaiga* (covenant). Latu Latai's research [15], explains the origins of the word *feagaiga,* describing the sacred gender relationship of sister and brother within the Samoan culture. The coming of Christianity to

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[13] Janet Pereira, "Spare the Rod and Spoil the Child: Samoan Perspectives on Responsible Parenting," Kōtuitui: New Zealand Journal of Social Sciences Online 5, no. 2 (2010)., p.12-36

[14] Samasoni Kupa, "Jesus Christ: The Revelation of "Fa'aaloalo"" (Malua Theological College, Samoa, 2006)., p.9-17

[15] Latu Herbert Latai, "Covenant Keepers: A History of Samoan (Lms) Missionary Wives in the Western Pacific from 1839 to 1979," (2016)., p.34-36

Samoa, views *feagaiga* bestowed upon a *faifeau* (reverend) and his church. This reflects the high regard our Samoan people respect and honour the *feagaiga* made between the *faifeau* and his church. From a cultural perspective, the *faifeau* is a representation of God. It is essential to include this cultural insight to highlight where ASD fits in our Samoan culture, during the act of worship. An ASD child being *ulavale*, would be associated with a stigma of disrupting the act of worship; resulting in the need to increase awareness of ASD within our families and the EFKS.

The integration of spirituality with the *fa'asāmoa* culture stems logic how the Samoan community come to understand life occurrences and their cause. As Jeannette Marie Mageo explained that the possession *ma'iaitu*[16] consists in a behavioral patios that derives from a cultural logic; With ASD, people are searching for answers to questions like why it happened? and who is responsible?

The research by Matthew Altiere and Silvia Von Kluge,[17]reflects upon the emotional stress experienced by parents of a child diagnosed with ASD. The research has been included to explain and reveal the reality parents to ASD children experience. ASD parents need to recognize their flaws in parenting. Why? Because it is essential towards progression and moving forward, to find intervention methods suitable for the ASD child.

Corsello's research [18] urges the need to implement early intervention methods best suited for a child with ASD. I have included Corsello's research to give informative

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[16] *Ma'iaitu* =Samoan term which means spiritual sickness relating to a person being possessed by a ghost or spirit

[17] Matthew Altiere and Silvia von kluge, "Searching for Acceptance: Challenges Encountered While Raising a Child with Autism," *Journal of intellectual & developmental disability* 34(2009)., p. 8-23

[18] Corsello, "Early Intervention in Autism.", p.74-85

information, regarding early age a child can get diagnosed for ASD. Corsello supports the early intervention methods we had put in place for Muzyc. It was successful to her progress and improvement in behavioural and social development. Therefore, early diagnosis of an ASD child becomes beneficial for the ASD child, extending to the family household.

Seyed Omid Sotoudeh Navroodi[19] draws the connection between increasing hope and life satisfaction for parents to ASD children. The research accentuates having a sense of hope, improving competency in parenting children with ASD. It is common for parents to feel stressed and lost in the world of ASD. In justification to the reality of emotions parents experience through the initial stage of diagnosis; Parents of ASD children come to realize that they need to support and help their children (ASD) in any way possible. This encourages the need to use all resources available to support and aid development of an ASD child.

Chapter Two of this thesis includes intervention methods used, to initiate good behaviour. The Aspire Child and Family Services website[20] emphasizes the need for parents of ASD children, to praise their child when they have accomplished a task. Praising a child with ASD, allows them to visualize their success and encourages a positive development for the child. Aspire Child and Family services also urges the need for family members (living in the same household), to work together to encourage positive parenting.

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[19] Seyed Omid Sotoudeh Navroodi et al., *Examining the Effectiveness of Group Positive Parenting Training on Increasing Hope and Life Satisfaction in Mothers of Children with Autism*, vol. 13(2018)., p.124

[20] Aspire Child and Family Services, "Discipline Strategies for Children with Autism Spectrum Disorder (Asd)," https://aspirecfs.com/blog/discipline-strategies-for-children-with-autism-spectrum-disorder-asd/.

Elizabeth O'nions[21] analysed the link between emotional and behavioural problems that ASD individuals face. O'nions research outlines the need to find intervention methods suited and fit well for the ASD child. ASD reflects spectrum, meaning that all those diagnosed with ASD do not reflect the same behavioural and social problems. Families need to seek intervention methods that best suits their loved one or child to initiate progress. When families locate these problems, then they can implement strategies and methods specifically suited to aid behavioural or social problem faced by the ASD individual. O'nions has named this in her research as treatment targets. By identifying these problem areas, helps establish consistency.

Khim Lynn Ooi[22] reveals the emotions experienced by parents, such as guilt, denial, hopelessness in not knowing how to parent a child diagnosed with ASD. Khim's findings in her research suggest all these emotions experienced by parents are due to lack of understanding and knowledge of ASD. It is important when your loved one or child is diagnosed with ASD, as parents, we have an obligation to make ourselves aware of what ASD is. Khim's research accentuates that the significance of hope when a child's (ASD) behaviour is improved. Spiritual hope preserves a sense of hope achieved through faith in prayer. Every milestone achieved by Muzyc solidified our hopes towards a hopeful future.

Filemoni Crawley's[23] work on people with disabilities supports the aim of this study. The sresponsibilities of the community and people with disabilities initiate building

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[21] Elizabeth O'Nions et al., "How Do Parents Manage Irritability, Challenging Behaviour, Non-Compliance and Anxiety in Children with Autism Spectrum Disorders? A Meta-Synthesis," *Journal of autism and developmental disorders* 48, no. 4 (2018)., p.172

[22] Khim Lynn Ooi et al., "A Meta-Synthesis on Parenting a Child with Autism," *Neuropsychiatric disease and treatment* 12(2016)., p.27

[23] Filemoni Crawley, "Thesis: 'Faia Model': Including People with Physical Disabilities within the Vaimauga I Sisifo Sub-District of the Congregational Christian Church Samoa" (2016)., p.60-73

communal relationships, extending to the context of the church (EFKS). Including people with disabilities in community activities is viewed as *"ordinary life"*, mirroring the miracle of Jesus healing the blind man as in John 9. Acceptance of their needs into our society and community is important to raise awareness and help, whether ASD or PWD. Crawley's work highlights the scarcity of resources reserved for people with disabilities and ASD in the Pacific and the EFKS.

I do acknowledge that it will take time and patience for Muzyc to understand what is taught in the *aoga sailiili*. But it is not impossible. By implementing ways to cater for Muzyc and her ASD, this can be achieved in Muzyc's time. There is no time frame to when a child should be ordained or *faaekalesia*. Louis Berkhof outlines the process of salvation in his book The History of Christian Doctrines[24] placing emphasis on the role of the church regarding Baptism entitlement to the salvation as promised by God through Jesus Christ.

2.3 Difference between Autism and *Ulavale*

Ulavale is not a form of Autistic behaviour, although it shows similarities to how an Autistic child would behave. ASD is a medical disorder[25] and not a cultural phenomenon. Because the symptoms of Autism first appear at an early stage of childhood, it can be misinterpreted as being *ulavale*. ASD have common traits and triggers, that maybe interpreted as being ulavale due to behaviour and attitude. ASD is not an attitude disorder, whilst *ulavale* reflects attitude and behaviour which happens sporadically[26].Perhaps the issue

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[24] Louis Berkhof, *The History of Christian Doctrines*(London: Banner of Truth Trust, 1969).,p.42-36

[25] David Farrugia, "Exploring Stigma: Medical Knowledge and the Stigmatisation of Parents of Children Diagnosed with Autism Spectrum Disorder," *Sociology of Health & Illness* 31, no. 7 (2009)., p.8-32

[26] Janet Pereira, "Spare the Rod and Spoil the Child: Samoan Perspectives on Responsible Parenting," *Kōtuitui: New Zealand Journal of Social Sciences Online* 5, no. 2 (2010)., p.11-17

is not the child’s behaviour. It is the community’s lack of understanding and consideration of early childhood development.

The word “*ulavale”* is mostly analysed with an attached negative connotation of being naughty. Such thoughts eliminate many findings of scholarly research on childhood behavioural development, creating an issue of misinterpretation. To some degree, the term *ulavale* associated with an ASD individual becomes a stigma, suggesting that the nature of an ASD individual is seen *ulavale* and difficult to deal with. It is important that we must not assume a child/person Autistic (despite showing signs and symptoms of ASD), without undergoing an official medical assessment confirming an ASD diagnosis.[27] We must be able to recognize and distinguish *ulavale* from ASD symptoms; they are similar when we look at it from nurturing a child’s early development. According to James E Johnson’s book Play and Early Childhood Development, accentuates on the word play. James E Johnson says when a child engages in the activity of play time, it is their way of communicating, social interacting, and expression.[28] This is no different in the light of ASD. That is because for an Autistic child/person, there is a need to explore and to communicate, but are bound by difficulties. A distraction to their efforts could lead to a meltdown episode, as their way of expressing frustration.

The most common definition of *ula* regarding this thesis about ASD is *ula* to mock or ridicule. It is *ula* in the sense of describing behaviour. The word *“vale”* is a description given to being foolish; In the context of a person not knowing how to behave in an appropriate

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[27] AJO Whitehouse et al., "A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia," *Brisbane, Australia: Autism Cooperative Research Centre (CRC)* (2018)., p.16-19

[28] James E Johnson et al., *Play and Early Childhood Development*(Scott, Foresman & Co, 1987)., p.40

manner.[29] When someone, most often a child is referred to as *ulavale*, it can be interpreted and used to pass judgement on an individual's behaviour. Labelling an individual naughty, based on their perception without any further investigation.

The Samoan understanding of *fa'aaloalo* (respect) is a wide concept. It derives from an evaluation of someone's behaviour towards other people and within communal gatherings. This concept of being *fa'aaloalo* in the Samoan culture greatly influences our evaluation of people within our EFKS church communities.[30]

Samoan people are religious people and attending church every Sunday, is essential to spiritual growth and blessings. The *falesa* (church building) is the place to worship God in a respectful manner. Thus a child that is *ulavale* would become an issue for some people including church leaders conducting church services. With this understanding of the word *fa'aaloalo*, Kupa explains the reason for the behaviour of the Samoan Christian.

In the Samoan community, giving *fa'aaloalo* to God is paramount. This is also the reason why the Samoan Christians reflect a high level of *fa'aaloalo* to the church ministers *(faifeau)* because; this is how Samoans perceives them. The minister is a representative of God. Therefore, an act of *fa'aaloalo* towards the *faifeau*, is also showing *fa'aaloalo* towards God. This is the perspective of a Samoan person reflected in his actions within the church. The act of giving to God is displayed through religious service, *faigataulaga* (offering) as well as caring for the *faifeau* and his family.

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[29] Pereira, "Spare the Rod and Spoil the Child: Samoan Perspectives on Responsible Parenting.", p.15-16

[30] Kupa, "Jesus Christ: The Revelation of "Fa'aaloalo".", p.9-10

The word *feagaiga* (covenant)**,** stems from the sacred relationship between a brother and sister. Latu Latai (Covenant Keepers: A History of Samoan (LMS) Missionary Wives in the Western Pacific from 1839 to 1979) defines the word *feagaiga*. *Feagaiga* was not only an indigenous concept central to gender relations in Samoa, but it also defines the dual relationship between the sacred and secular in Samoan epistemology and worldview"[31]. With the indigenous meaning of the word *feagaiga***,** it has now been bestowed upon the sacred relationship between the *faifeau* and his church. This process reflects the continuity of Samoan ideas about religion. The hope in the minds of Samoan Christians, views a blessing from a *faifeau* is also a blessing from God.

Kupa[32] brought his understanding of respect to describe the life and ministry of Jesus Christ, and His redemptive work on earth. In doing so, Kupa says, "Jesus Christ is *fa'aaloalo*"**.** It is a statement that derives from his understanding of Jesus Christ and the action of his redemptive work. According to Kupa, *fa'aaloalo* is seen in the person of Jesus Christ as well as in His ministry work. It is said that Jesus Christ knew and understood the significance of relationship between Himself and other people, known to the Samoans as the *"va tapuia"*. Jesus Christ also came as a servant who served the needs of many people in His ministry. Jesus Christ was the one who gave wholeheartedly not only to the needs of the poor and the oppressed, but also His own life for the sins of the world. This is the Samoan view of religion, the importance of maintaining the dignity of the worship of God in the church. It is believed that this is also the reason why Samoan's value peace in religion, because of the priority and reverence for God through which blessings come from.

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[31] Latai, "Covenant Keepers: A History of Samoan (Lms) Missionary Wives in the Western Pacific from 1839 to 1979.", p.36

[32] Kupa, "Jesus Christ: The Revelation of "Fa'aaloalo".", p.15-16

A conclusion of a personal survey conducted with some of the church members within the EFKS, shows varying views. Some of the responses by those I interviewed referred to a child being *ulavale* as “kids are just being kids”[33]. However, parents of ASD children would not be immune from the complaints of those that disagree. From a cultural perspective, some people say that children being *ulavale* in church, should be dealt with immediately. Such behaviour is disrespectful to others and ultimately to God. A resolution to this issue is when a parent would either give food to try and bring the child to a calm state. If that does not work, then the child and parent would withdraw most often outside away from the place of worship *(falesa)* and remain there until the worship service is finished. For ASD, we most often had to resort to withdrawing Muzyc away from the worship service when attending church (early ASD diagnosis). We feared that something would set or trigger Muzyc into a meltdown. Through love and understanding of Muzyc and her ASD, we were able to find solutions for Muzyc to cope during worship at Church on Sundays, without the need to take her out of the worship. With the help of Muzyc’s sensory items, we were able to have Muzyc present in the act of worship.

We have discussed the word *ulavale* and its literal meaning. The word is a conclusion to an evaluation of a person most often a child, based on personal behaviour. I have come to acknowledge that the word *ulavale* is not only a broad statement, but also judgemental. Labelling every child that could not meet the requirements influenced by a cultural perspective while in the process of worshiping God.

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[33] This is an interview conducted with a member of Fasito’outa EFKS church on 2nd January 2021 12:00pm he stated “*O le tamaititi lava ia e ulavale, e i ai lava le taimi e malamalama ai”.*

2.4 Muzyc: A Personal Case Study

Being parents to two Autistic children, my wife and I have come to learn and experience many elements regarding Autism. It was extremely difficult for both of us to accept being told by our family and other people, that your child should be taken in for an assessment because she might be Autistic. At first it was not an issue because both my wife and I were not aware of what ASD was. The journal article titled "Searching for Acceptance: Challenges Encountered while Raising a Child with Autism", conducted a survey recording the responses and challenges of many parents of ASD children. The article written by Matthew J. Altiere and Silvia Von Kluge describes the emotions of these parents and the five challenges as development, questioning, devastation, solutions and growth. Altiere and Von Kluge "the described confusion that resulted from their child's behavioural presentation and the feelings of loss and devastation that occurred after discovering their child has Autism." [34]However despite the challenges, the ASD parents were willing to do all they could, to help accommodate for their ASD child.

When our daughter was diagnosed with ASD, life seemed hopeless and we were both in denial that Muzyc could be Autistic, being ignorant to listen. We felt overwhelmed with the reality of knowing that our daughter would encounter challenges at such a young age. Like any parent, we had high expectations, hopes and dreams for our child to live a normal life. There was no sense of direction on how and where to begin, as we had to come to terms to accept and learn the world of an Autistic child. Eventually, the more we were exposed to the world of ASD, we came to the realisation that our Muzyc's diagnosis was a blessing in disguise. Our Muzyc at the age of 2 (prior to ASD diagnosis) showed her area of strength in

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[34] Altiere and von kluge, "Searching for Acceptance: Challenges Encountered While Raising a Child with Autism.",p.23

memorising shapes (trapezium, dodecahedron, rhombus), the alphabet and numbers counting to 100 and backwards, (which is her core ability) and displaying a high level of attention to detail as a visual learner. Where Muzyc excelled in this area of life, she lacked communication and social skills to which she was unable to conversate with us, on what she wanted to eat, or how she was feeling (emotional aspect). Little did we know, Muzyc at the age of 2 gave us her parents an insight to the beautiful world of ASD.

From the eyes of a parent, our daughter was perfect. The thought of Muzyc could be Autistic, never left our minds. As Muzyc reached the age of three, many tasks that we had expected her to accomplish on her own were major challenges for her without someone helping and guiding her. This includes going to the bathroom, showering, putting on shoes and clothes. Muzyc displayed a lack of speech, not a single word she was able to speak and communicate and with all these signs, we became concerned. We finally came to a decision and ventured out to seek help. We first contacted our family doctor and raised our concerns asking how to go about getting an assessment done for Muzyc for Autism. Our family doctor referred us to a Paediatric specialist who specialised in diagnosing children with Autism. My wife and I were placed on the waiting list to see the specialist in which we waited six months for. When this day came, we finally got the official diagnosis that Muzyc is Autistic at the age of 4 years old. Children suspected of ASD can medically be diagnosed as young as 2 years old as documented by Christina M. Corsello. [35]

The confirmation of Muzyc’s diagnosis was overwhelming for us as parents to find out that Autism was a permanent disorder, and it has no cure. Immediately as parents, it felt like all hope for our daughter seemed at a loss knowing that our Muzyc was not going to have a

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[35] Corsello, "Early Intervention in Autism.", p.26-27

normal life. That was our immediate response to words like no cure. Research has shown that parents with ASD children, highlights an intense level of stress and confusion during the period before and after they receive an official diagnosis. “Although the quest to help their child may alleviate some negative feelings, the stress increases when parents realize that there is no cure for Autism.”[36] Hope is considered as an essential element and a coping resource for humans in adapting to difficult situations, especially with those who have loved ones diagnosed with ASD. Navroodi states: “Hope can be described as multidimensional, dynamic, powerful healing factor that can have an important role in adjustment to the trouble.”[37] We turned to God in prayer to guide the way and our despair turned our hearts and minds to the prospects of hope for Muzyc. We had to accept wholeheartedly Muzyc’s diagnosis, to enable to help guide and pave a way for Muzyc to improve her everyday life. We were the founding key to hope through love and understanding of Muzyc and her ASD. According to Moltmann, the God we speak of is not a God of this world or a God out of this world, but a God of hope. And how does this belief relate to all our hopes? We do not understand and know the outcome of all our hopes for the future, because we do not know what will happen in the future. Furthermore, Moltmann elaborates by saying, if there was no hope in Christian society, we neglect the world. This explains how humanity seem to create many conflicts between each other in the world today. It is the essence of having a living hope to have a purpose of living for what we hope for in life.[38]

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[36] Altiere and von kluge, "Searching for Acceptance: Challenges Encountered While Raising a Child with Autism.", p.21

[37] Sotoudeh Navroodi et al., *Examining the Effectiveness of Group Positive Parenting Training on Increasing Hope and Life Satisfaction in Mothers of Children with Autism*, 13., p.42

[38] Moltmann, *Theology of Hope* , p.40-41

2.4.1 Our Contribution in Muzyc's Intervention Programme

We thought the early intervention programme was for Muzyc only. Surprisingly at the end of the month, the focus of the speech, occupational therapist and the phycologist, shifted from our daughter to us. It did not make a lot of sense at first why a speech, occupational therapist and psychologist would want to spend valuable time and effort on us, instead of putting more emphasis on Muzyc. However, as we allowed ourselves to listen and have an open mind to what was presented, we came to acknowledge our own flaws in raising our daughter living with Autism. Every parent loves their children and so do we with Muzyc. In contribution to helping our daughter succeed and develop further, strict disciplinary methods were set in place. Not only for Muzyc to obey and follow, but also for us (parents) who now has the role of putting these methods into practice.

There has been documented research, emphasizing focussed parenting group programs aimed at instructive effective methods for parents raising ASD children. As documented by the research carried out by Iranian psychologist Soutoudeh Navroodi, outlines that it is critical that parents of ASD children, must understand their child's needs, to increase development in life for children with ASD. She exemplifies that by instructing effective and positive focussed parenting programs (centred on the parents) they can "instruct their children and reduce the challenging behaviours that are derived from their expansive needs; moreover, such programs can help parents evaluate their children's interfering behaviours appropriately. Also, parents training programs increase parent's competency".[39] Even though Muzyc was on the path of building development in her everyday life, but we too were building strength in our new style of parenting to cater for Muzyc and her Autism. "Positive parenting programs

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[39] Sotoudeh Navroodi., "Examining the Effectiveness of Group Positive Parenting Training on Increasing Hope and Life Satisfaction in Mothers of Children with Autism.", p.57

have a positive effect on parent's lifestyle, self-efficacy, satisfaction, compatibility, relationships, and taking care of the child."[40]

Each child with Autism varies in terms of where they sit on the ASD scale. Each child with ASD has their own specific needs that varies from other children diagnosed with ASD. For my wife and I to be able to implement and carry through with the early intervention programme for Muzyc, it was essential for us to understand Muzyc and her ASD, understanding Muzyc's behaviour that seemed challenging. With this knowledge we were able to implement specific parenting methods catered for Muzyc.

2.4.2 Method 1: The Naughty Chair

The naughty chair was first introduced by the psychologist who cares for Muzyc. This is sitting Muzyc in a chair every time she does not comply with the instructions given to her. She would have to remain sitting on the designated chair we assigned in our living room, until she was given permission to leave. The time allocated for the naughty chair was 30 seconds. This was a very heart-breaking method for us in the beginning. I took the first try of sitting Muzyc on the naughty chair, as the speech, occupational therapist and psychologist evaluated my performance from a distance. My daughter screamed, kicked, and cried in frustration as she tried to leave the chair numerous times, but I repeatedly placed her back on the naughty chair. With the 30 second time frame allocated for the naughty chair, we did not expect for this exercise to now last for thirty minutes. As a father I felt awful for what I was doing to my daughter. At this point, I just wanted to pick her up and comfort her and forget about the session. I was reaching my breaking point. At this point the psychologist approached me and whispered in my ear, "If you love your daughter and you want to help her

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[40] Sotoudeh Navroodi et al., *Examining the Effectiveness of Group Positive Parenting Training on Increasing Hope and Life Satisfaction in Mothers of Children with Autism*, 13.p.59

through life, do not show your emotions and do not give in to her". At forty-five minutes of supervising Muzyc in the naughty chair, she stopped crying. She stared at my eyes looking back at her in silence. We finally reached a breakthrough with the naughty chair. I got Muzyc's attention full of curiosity, almost as if she were waiting for further instructions. With Muzyc achieving this goal of sitting in the naughty chair for 30 seconds at 45 minutes, the psychologist told me, "Now you can hold her and congratulate her for listening".

According to the psychologist the session that I had just participated in, was the opening of a new thinking in Muzyc's mind. A session on the naughty chair was to establish whose "boss" in the family. Not Muzyc but her parents. Muzyc had to learn the significance of listening and obeying the instructions, crying was not a proper way of communicating, reinforcing, and encouraging the need for her to use speech language. Problem behaviour that is commonly found with ASD children, includes exasperating characteristics such as self-harm, running away, aggression, property damage and challenging behaviour in public. Mainly when there has been a change in their normal day to day routine, unfamiliar environment, or sensitivity to their senses. The emotions and behaviour of ASD show a high level of irritability (for example anger, frustration, distress, meltdowns) and constant non-compliance with everyday commands displaying significant challenges. For parents raising children with ASD, these cues are critical to learning and understanding the target areas of their child's behaviour. Identifying these target areas helps teach and develop ways to help their child find another way to cope in these situations. Elizabeth O'nions concept "these behaviours have been identified as important treatment targets in children with ASD." O'nions study centred around exploring the different approaches used by parents living with ASD children by reflecting on the following approaches:

> “(1) accommodating the child; (2) modifying the environment; (3) providing structure, routine, and occupation; (4) supervision and monitoring; (5) managing non-compliance with everyday tasks; (6) responding to problem behaviour; (7) managing. distress; (8) maintaining safety and (9) analysing and planning”.[41]

The naughty chair for Muzyc was essential for progress and development. It taught Muzyc to listen and obey commands given to her by her parents. Over time, Muzyc adjusted and understood the purpose of the naughty chair.

2.4.3 Method 2: Removing privileges

It is importance not to reward bad behaviour. Simple things like, going shopping or getting a new toy, should all be given to Muzyc in a form of a reward. Prior to giving Muzyc a *treat,* we had to ask her to do something simple like putting the rubbish in the bin or picking up her toys and placing them in the toybox. When Muzyc achieved either of these tasks, then going shopping would be rewarded because she listened. Muzyc understood that good things happen because of good behaviour. All good things given to her is a privilege. Muzyc had to learn that good behaviour means good outcome.

According to the Autism Inspires Family organisation website, the methods that we outlined have been effective towards Muzyc’s development (behavioural aspect). “Establishing consistency and becomes a constant reminder of rules set out by parents.”[42] For Muzyc the naughty chair and taking her privileges away was a constant reminder for her that these two methods highlighted the consequences. The challenge for us was to try and maintain the consistency, to implement these methods accordingly. The naughty chair and taking Muzyc’s privileges away were soothing for her (once well adapted to these methods).

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[41] O'Nions et al., "How Do Parents Manage Irritability, Challenging Behaviour, Non-Compliance and Anxiety in Children with Autism Spectrum Disorders? A Meta-Synthesis.", p.39

[42] Services, "Discipline Strategies for Children with Autism Spectrum Disorder (Asd)"., retrieved 20/05/2021

She was able to refocus her senses with the goal of achieving good behaviour and complying to everyday commands. When Muzyc was able to achieve the goal of sitting still in the naughty chair, we praised Muzyc when she complied. “When bad behaviour is corrected, offer positive reinforcement by praising your child when exhibiting good behaviour. This allows for the child to visualise their progress.”[43]

2.4.4 Family Involvement

The speech, occupational therapist and the psychologist now turned their focus on the whole family living within household. The focus was to have everyone living in the household with Muzyc, aware and contribute to her development. This is known as the family circle. Family involvement is essential to the development of an ASD child. Encouraging this type of family relationship within the household, allows an ASD child to feel secure and loved.

There were times Muzyc would try and avoid the naughty chair by seeking what is known as the weakest link to the family circle. At the beginning of Muzyc’s intervention programme, she knew that her grandmother was her way out of unacceptable behaviour without any consequences. Putting Muzyc in the naughty chair was heart wrenching as parents when applied, and that was the same for Muzyc’s grandmother. Muzyc’s grandmother found it difficult to accept the naughty chair exercise in the beginning and would always resort to the room to avoid hearing Muzyc’s screams and cries. Muzyc’s grandmother was a challenge for us in the beginning implementing the naughty chair. When it became overwhelming for Muzyc’s grandmother, she would approach my wife and I and scold us for what we were doing to Muzyc, disrupting the naughty chair intervention process.

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[43] Speaks, "What Is Autism"., retrieved 20/05/2021

We knew exactly what our mother was feeling. Research and study show that all these emotions experienced by other members living within the same household are normal. As noted in Khim Lynn Ooi's study:

> "Parents and family members (living within the same household) go through an initial stage of denying the diagnosis due to lack of understanding of the disorder, doubt on the diagnosis given or disbelief that such a thing would ever occur to their child or loved one. Several parents and family members living within the same household felt guilty and blamed themselves and hopeless within their inability to help their child and or loved one."[44]

It was the sense of guilt and heart-breaking experience when applying the naughty chair, however we made the time to explain to our mother what we needed to achieve within our household in terms of Muzyc's development.

Now that our mother was aware of the purpose of the naughty chair, she was onboard with the intervention methods we had to put in place for Muzyc's progress and development. When Muzyc did not obey us her parents, she turned her efforts to her grandmother. With our mother's full support of our efforts, Muzyc was now at a loss, knowing that the loophole she had established within her household, was a loophole no more. All family members were now working together as a unit to help Muzyc's development, reflecting upon the positive emotional responses. Acknowledging ASD by all family members living within the same household, we were now able to "begin coping with it and to reconcile any guilt or self-blame for attributing the child's behaviour to bad parenting."[45]

The models below highlight the family circle. On the left, shows the family with all participants living in the same household working as a team/unit. The model on the right

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[44] Ooi et al., "A Meta-Synthesis on Parenting a Child with Autism.", p.63

[45] Ibid., p.63

reflects the family circle with the "grandmother" detached from the model outlining a loophole.

Figure 1.1- Family Circle Model

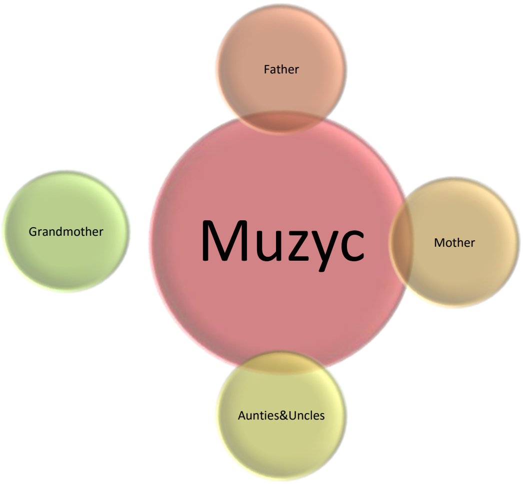

Figure 1.2 - Family Circle Loophole Model

Chapter Three

Involvement of the Church, Findings within the EFKS, ASD and Salvation

3.1 Involvement of the Church: Part of the Family Circle

My daughter was born in the year 2012, the same year we first attended Meadow Heights EFKS in Melbourne Australia. According to Rev Fiaalua'e Tiata the current church leader of Meadow Heights EFKS church, he had a fair background knowledge of ASD. However, he was not familiar of its behavioural symptoms, which affects the intellectual ability of a person to learn and interact with other people. After educating Reverend Fiaalua'e and his wife Manuula about ASD and what to expect from a person that is living with ASD, Reverend Fiaalua'e and his wife explained Muzyc's diagnosis to the church. They both used the information we had relayed onto them about ASD, emphasising that the church was to participate in helping Muzyc throughout her training to further develop her basic skills in communicating with life and church.

It was a great accomplishment knowing that our EFKS church community was now aware of our Muzyc's diagnosis and the world of ASD. However, for us as Muzyc's parents, we were still hoping for something greater. Taking Muzyc and Samson to church was not enough. As parents we envisioned, Muzyc participating in everything that was going on in the church like attending Sunday school, taking part in a Sunday school play for White Sunday.[46] An event so familiar to parents and children over the years who do not have

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[46] White Sunday is one Sunday that is dedicated to every child within the EFKS. An event that happens once a year in the month of October.

children with special needs. But for parents with children that are on the Spectrum, just to have their child with ASD present and participate in these programs is a dream come true.

We were aware of all the challenges that we had to work with to succeed in having our daughter participate in Sunday school lessons and church services but, it was not impossible. The methods that we had used in helping Muzyc's development at home, was now used within the context of church. This can be an example of a practical model, merging the *'aiga* and family of God in finding answers. By doing this, Muzyc recognised that her behaviour at home, should be the same within the church. She was aware of the interventional methods used at home for exhibiting bad behaviour. We were now working together with our church leader (Rev. Fiaalua'e and faletua Manuula) as well as our church family emphasizing the family circle concept that was used at home now incorporated in the context of our EFKS community.

The surveys that I conducted with selected members of the EFKS church included some church leaders, have suggested the lack of awareness within Samoa EFKS church community regarding ASD. Many of the church members that I interviewed are all similar with their responses when they were asked to define ASD.

The word *ma'i*[47] was a term frequently used by my participants to explain ASD. I expected this, considering the lack of understanding and awareness our EFKS people have about ASD. The word *ma'i* was best to describe someone they saw fit their description of special needs outlining an obvious mistake. The word *ma'i i*n the Samoan language refers to many types of special needs either mute, blind or paralysed. It also refers to viral infections

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[47] *Ma'i* = Sickness

like catching the flu or other bacterial infections. On the other hand, the word *ma'i* can also be used to describe spiritual sickness *ma'i aitu* in relation to a person sought to be possessed.[48] Rev. Filemoni Crawley refers to the cause of *ma'i* reflected in his study as a curse upon the child with physical or intellectual impairment, influenced by an indigenous and cultural view. "The indigenous believe that a curse is imposed on families or individuals who violate the faiā."[49]. Faiā as defined by Rev. Crawley emphasizing "the relationship that is full of responsibilities and actions."[50] Crawley outlines that family especially the parents' relational connections within the community, are the enablers for PWD (People with disabilities) or ASD to engage and participate in "communal and relational living".[51]

Hence, I do argue that the word *ma'i,* is not a suitable term to describe or address all types of special needs person/child. Although some had fair knowledge and awareness of what Autism is, it came to my attention when conducting my survey, many of those I interviewed generalised *ma'i* to label individuals with special needs. In actual reality, all special needs have their own specific needs, and understanding these specific needs works effective to help, approach and engage with the diversity of special needs that exist in our society.

In many interviews with the EFKS church leaders, I was fortunate that they offered to speak about their methods of approaching an individual with autism or *ma'i.* Most of the EFKS church leaders I interviewed, spoke of how they would have dealt with people similar *(ma'i).* Each *faifeau* had a different approach. One of the church minister/leader stated,

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[48] Jeannette Marie Mageo, "Ma'i Aitu: The Cultural Logic of Possession in Samoa," *Ethos* 19, no. 3 (1991)., p.30-33

[49] Crawley, "Thesis: 'Faia Model': Including People with Physical Disabilities within the Vaimauga I Sisifo Sub-District of the Congregational Christian Church Samoa.", p.67

[50] Ibid., p.75

[51] Ibid., p.75-76

"every child is the same even those that are considered *ma'i*, if you keep at it, they will soon come to understand what you are trying to do".[52]

Some took the biblical approach of suspecting the parents are the cause of the *ma'i*. The *faifeau* saw the child with autism as the consequences of a parent sinning towards God. He stated that, parents with children that are *ma'i* should consider practicing *"anapogi"*.[53] *Anapogi* is the Samoan word for fasting which is a religious practice that involves giving up something that you desire for a set period of time,[54] or something that we need. From my understanding of the Bible, this approach from the Old Testament highlights sickness as revelation of God's judgement upon someone that had sinned which is further emphasised in the dialogue between Job and his friends.[55] Therefore, considering aid or assistance with individuals who have special needs, fasting is significant to seeking God's mercy and forgiveness on the child and his/her parents, so that the child would be cured.

3.2 EFKS *Faifeau* and their families living with a child diagnosed with ASD

I was blessed to have the opportunity to discuss my thoughts on raising awareness for autism in the EFKS, with church leaders that have children with ASD. All participants responded to the conversation willingly. Both church leaders reflected a high level of awareness for autism, acknowledging the approach to their needs, and behavioural issues. Both church leaders showed similarities in approach. One stated, "that although it was a

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[52] Rev. Sakaio Maiava, interview by Aunese Anau, 15/01/2021, 2021.This is an interview conducted with Rev Sakaio Maiava on 15 of January 2021 at 3:00pm he stated "O le tamaititi lava ia e a'oa'i ma fa'atonu, e i ai lava le taimi e malamalama ai"

[53] Rev. Fa'ataualofa Mata'i, interview by Aunese Anau, 13/01/2021, 2021.This interview was conducted with Rev Fa'ataualofa Mata'i on the 13th of January 2021 at 8pm. He stated, *"E tatau ona mafaufau e anapogi"*

[54] Scot McKnight, *Fasting: The Ancient Practices*(Thomas Nelson, 2010)., p.71

[55] *Holy Bible/New Revisedstandard Version*, (Peabody, Massachussetts: Hendrickson Publisher, 2011).

challenge to have my son participate in Sunday school and church services, I knew it was not impossible, and it could be done, just needed to have patience".[56] The importance of having church members aware of Autism and its symptoms was also raised upon discussion. He stated, "it was not easy at first and yes we were also aware of many criticisms about our boy from time to time, but we knew that they did not understand".[57]

Reflecting upon my experience with ASD, I also agree that it is indeed challenging to introduce an Autistic child to Sunday school, and remain still during church service worship. This is because a person/child with ASD has a high level of attention to detail in their mind "being in their own world"[58]. This prevents an Autistic person/child to be aware of the reality of their surroundings (church service worship/Sunday school). Rev Roma Enosa and his wife advised that it is important to educate and explain the symptoms and needs of an Autistic person, to their church members. As church members were now aware of Autism, Rev. Enosa's church community were able to assist and aid his son effectively. Hence, their son can roam anywhere within the village without worrying about their son's safety, because everyone in the village/church were aware and understood. "Everyone in the village always looks out for our son and always has a popo (coconut) whenever he goes around to any of the houses of the village because that is his favourite thing to do was collecting popo.[59] He also emphasised the importance of being patient. "All we had to do was tell them (church members). Now that the church understands, they are now a big help". Furthermore, Roma

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[56] Rev. Martin Mariota, interview by Aunese Anau, 01/01/2021, 2021.This is an interview conducted with Rev Martin Mariota who has a son that is autistic on the 1st of January 2021 he stated "e taua lava le onosa'i, e le faigofie ia maua le taumafai e ave le tama I le aoga aso sa ae peita'i na faifai a masani"

[57] Rev. Roma Enosa and wife, interview by Aunese Anau, 20/01/2021, 2021.This interview was conducted with Rev *Roma Enosa* on 20th of January 12:00pm he stated "*e le'i faigofie ona e le'i malamalama tagata o le aulotu"*

[58] Roberta L Woodgate, Christine Ateah, and Loretta Secco, "Living in a World of Our Own: The Experience of Parents Who Have a Child with Autism," *Qualitative health research* 18, no. 8 (2008)., p.19-20

[59] An interview conducted with Rev Roma Enosa on 20th of January 12:00pm he stated *"O le taimi nei ua pule a le tama ia, e alu solo i fale o tagata o le aulotu, ua masani ai a la tagata uma o le aulotu".*

urges to remind our EFKS church communities to have patience when dealing with individuals who are Autistic, but also individuals with special needs in general.

I asked both church ministers/leaders that have Autistic children, if they have ever, experienced any situation having an Autistic child running around making all the noise, while in a moment of conducting a Sunday service. According to Rev Roma Enosa, taking his son to church every Sunday was an obligation. This was to enable to cater to his son's development and awareness of what church is and its significance to spiritual learning. Furthermore, he accentuated the fact that his Autistic son's symptoms, was never a problem for him in the context of conducting a Sunday service. His ASD son's behaviour was obviously a problem for some of the church members not being aware of Rev. Enosa's son's diagnosis of ASD. However, being patience is vital. Time plays a major role in people's learning and awareness of what ASD is and its behavioural issues. Time also explains the meaning and importance of salvation to a person with ASD. However, I believe in their own time they will come to understand. Rev Roma Enosa's method of introducing ASD within his EFKS church, was essential. The church community shared responsibility in looking out for his son's safety and comfortability in church. In my view, Rev. Enosa's utilization of his congregation to raise the level of awareness of ASD, proved to be beneficial not only for Rev. Enosa's son and themselves, but also to their community.

Rev. Martin Mariota who also has a son with ASD, introduced the church into the life of his son by emphasizing on his son's love interest of painting and colouring. Rev Mariota and his wife used their son's love of painting and colouring to help their son remain calm while in the act of worship setting. From this, he saw an opportunity to merge the significance of church into the routine of their ASD son by involving the activity that their son loves to do, painting and colouring (sensory aid). As a result, this method offers two beneficial results:

1. Martin’s son would be at a calm state enabling the church members to worship at ease and together with their ASD son present.
2. Going to church is now incorporated within their son’s weekly routine.

Rev. Martin Mariota spoke about the progress and development of his son within the church, but also with his church community on a wider scale. He stated that through time, their son became aware of his surroundings, shifting his focus from colouring books to acknowledging church and Sunday school.

3.3 ASD and Salvation

I attend church because I know and accept the salvation that God has prepared for the whole world, through Jesus Christ who died and rose again victorious from death and the grave. This is also the assurance that my family and I have been saved. What about children with ASD, are they entitled to Salvation? The answer is yes. Everyone including individuals with ASD. Soteriology (Doctrine of Salvation) is defined by theologian Louis Berkhof’s book The History of Christian Doctrines. Bekhof says that the real Christian is one who knows God, believes that he is accepted by God, obeys the principle of the Gospel, and initiates the Holiness of Christ. [60] Berkhof also regards the atonement of Christ as the universal-Christ[61] who suffered and died for the purpose of saving all, without any exception. Christ made salvation possible for all, including those living with ASD. The only requirement that God asks of us is to accept salvation through faith: “with it man enters increasingly on

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[60] Berkhof, *The History of Christian Doctrines*., p.27-33

[61] Ibid., p.35

the possession of the blessings of salvation"[62]. Bekhof explains this further by describing the process of salvation. Children born of Christian parents, who cannot yet resist the grace of God, are regenerated in baptism, and receive the gift of faith. It is through faith they are then justified, receive the forgiveness of sins, and adopted as Children of God[63]

Baptism is to bring the child into the family of God identifying these children as children of God. If so, what about children with ASD and others with special needs? It is all children including children with ASD. In the concept of baptism, there is a commitment and obligation by all who are members of the congregation of the Church. The purpose is for the Church community to work coincide with the parents of the baptized child to nurture, protect, and discipline all children, to know and develop their spiritual living and growth to walk in God's ways. Rev. Crawley details the obligation of the church when the church makes their vow before God to withhold those responsibilities. "We proclaim that through the guidance of God, we will pray for this child, and his/her parents, we will also perform our duties of teaching and assisting this child so that he/she may grow and become a Christian and member of church." [64] The role of every EFKS member is to make sure that "service is provided to ensure everyone is able to attend, enter and worship God without barriers." [65] If all children should be baptized, then the role of the church community in nurturing every child stays the same, despite either ASD or normal.

Next is the consideration of bringing Muzyc into the sacrament of the Eucharist. As Christians, we have a fair understanding about the importance of receiving the blood and

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[62] Ibid., p.39

[63] Ibid., p.39-42

[64] Crawley, "Thesis: 'Faia Model': Including People with Physical Disabilities within the Vaimauga I Sisifo Sub-District of the Congregational Christian Church Samoa.", p.80

[65] Ibid., p.80-81

Holy body of Jesus Christ, through the sacrament of the Eucharist. The Eucharist is a ceremony of remembrance and thanksgiving of God's redemptive love through the death and resurrection of Jesus Christ, establishing salvation for the world and the atonement for our sins. These are the things that the Christian should ponder about. It is to feel the importance of participating in the sacrament of the Eucharist. Bekhof portrays the *Eucharist* in which a person bestows participation in immorality.

Through the communicant (person receiving the Holy Communion) enters the fellowship with Christ and the divine spirit. [66] For this reason, I asked Rev Fiaalua'e[67], how it would be now, when the time comes for my daughter to be ordained *fa'aekalesia* to have her partake the sacrament of the Eucharist. Rev Fiaalua'e had no difficulty in answering this question. He said Muzyc's presence in the church had opened his mind to what he had never considered in his ministry. He is now familiar with Muzyc and the symptoms of her ASD. He is aware that it takes time for Muzyc to understand something, but that does not mean that Muzyc will not be able to develop an understanding about the importance of participating in the ceremony of the Eucharist, in the future. He also stressed that Muzyc's parents would continue to work together with the help of the congregation, to help Muzyc in any way so that she can continue to develop an understanding of things that are happening within her church. He said, give Muzyc time. As she grows up within the church, in her own time she will understand. There is no time limit for a child to be ordained *fa'aekalesia* within the EFKS. It is up to the parent to bring the child in to participate for what is known to the EFKS as the '*aoga sailiili*[68] whenever they think is the right time.

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[66] Berkhof, *The History of Christian Doctrines*., p.42

[67] Rev. Fiaalua'e Tiata and wife, interview by Aunese Anau, 20/01/2021, 2021.This is an interview conducted with Rev Fiaalua'e Tiata on 20/01/2021, 17:52pm (Samoa Time)

[68] The schooling administered by the minister is appropriate for children to be included in the sacrament of the Eucharist. The church minister teaches the child the importance of partaking of the sacrament.

This is what we hope to eventually happen for Muzyc in our EFKS church. Reverend Fiaalua’e and his wife, and members EFKS Meadow Heights, Melbourne congregation, understood the nature of our daughter's ASD. Rev. Tiata and wife, together with our congregation family held the same responsibility as ourselves. This was to help Muzyc and her transition to church and spiritual growth. Thus, Muzyc was beginning to understand proper conduct in the church and worship.

Chapter Four

A Way Forward

4.1 A Buddy System Framework

A thorough contemplation of the source of this thesis is deeply rooted in two biblical texts. I hope will do justice in proclaiming the unfathomable love of God, He has shown to us all. John 9:3 “Jesus answered “Neither this man nor his parents sinned; he was born blind so that God’s works might be revealed in him”.[69] I will not appeal a debate on the theological aspects of this verse, but it is a verse to purely take on face value as disclosed by the Savior. It is a proclamation of Hope. Spirally propelled upwards and forward, not only for the parents and the church (people concerned, setting), but so much more for those with ASD and any debilitating ailment.

The text provides a sound basis for the faith and love to be shown by the parents, which the one greatest barrier can be overcome: self-blame and shame. It is not a reason to brush off any responsibilities or to belittle a person’s duty to those less fortunate. No one is to blame. The crowd were looking and asking for a source to validate their fears, but this aim was made void by Jesus’ answer. It is not a reason to blame but a reason to show love. What cannot come from man but only from God Himself. This enables the parent to fully concentrate and play their role to the fullest, ultimately feeling a sense of worth and at the same time, an accomplishment that would not have been achieved otherwise.

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[69] *Holy Bible/New Revisedstandard Version*.

In turn, Jesus' answer is a wake-up call for the crowd, or in our case the church. We should not seek the source of ailment of seek to appease our sense of worth, but we as a church should seek the love of God. Rev. Crawley reiterates the healing of the blind man by Jesus symbolizing the "inclusion of the blind man into society."[70]Therefore, Jesus viewed disability "as an ordinary life." [71] This love will enable us to exact our standing and our worth as a church, to those with ASD. In turn, understand our standing, by ridding our hearts of all misconceptions of a sense of one is better than the other because of not being whole. Meaning the healing of Jesus of the blind man "opens the eyes of others in how God's relational love through community and church that provides PWD and ASD with a sense of belonging."[72] Jesus' reply is a straightforward wake up call, so that the love of God be made manifest.

Finally, to the Autistic child; if there is any way to show the love of God, I feel inadequate and worthless. Suffice to say, the only way I can show the love of God is in a form of a heartfelt apology. Just to say I am sorry for my ignorance and my finger pointing, and any other time I have thanked God that I am not like you, not whole, weak, and frail, in need of constant help. I now understand that you are like that, so I can show the love of God to you, through you my calling, and the calling of the church can be fulfilled. This will easily lead me to the next bible verse. Matthew 19:14 but Jesus said, "Let the little children come to me, and do not stop them; for it is to such as these that the kingdom of heaven belongs".[73]

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[70] Crawley, "Thesis: 'Faia Model': Including People with Physical Disabilities within the Vaimauga I Sisifo Sub-District of the Congregational Christian Church Samoa.", p.81-82

[71] Ibid., p.82

[72] Ibid., p.82-83

[73] *Holy Bible/New Revisedstandard Version*.

Once again, I will not petition the various disciplines but only to highlight who are we to go against the will of the Savior who wants to have fellowship with our children? He wants to hold them and embrace them, lift them on his lap where His glorious face is just a few centimeters away from theirs. In turn making the face of Autism radiate a love to shine upon us all, manifesting in the love of God; His stern voice was immediately to his beloved disciples who thought otherwise and to the crowd (setting or church).

This initial voice is to us His faithful individuals. We always seem to put children unconsciously or purposely those with ASD, in a setting we deem worthy and according to our likes and beliefs; but fail to understand our Savior just wants all the children as they are. Let us not stifle their abilities, but in turn stifle our abilities to have the ability to show the true love of God, by letting our Autistic children come to Jesus.

4.2 The Buddy System: A Cognisant

Upon studying and getting to understand ASD, many a time I witnessed the abilities of my daughter through our minister’s daughters, which I was not aware of. This prompted me to question if this could be a method, to help those with ASD to strengthen and encourage them, making them feel comfortable in their surroundings, especially that of Church.

The buddy system is not a new concept. It is prominent within the sociological and physiological arenas for the well-being of the ASD individual. Little is written or non-existent within the church. Suffice to say, a discourse must materialize, and I propose some aspects of a buddy system model, to be aptly and skillfully manifested with the church.

I would like to propose a three-tier buddy system to be initiated firstly by ASD parents:

Buddy to ASD
Buddy to Parent
Parent to ASD

This system will be soley based on the work I witnessed between my daughter Muzyc and the interaction with our church leader’s daughters.

4.2.1 Buddy to the ASD

The first tier is the buddy to the ASD. This phase is important. I will name it the choosing or the affiliation period. This is the period where the Autistic child chooses his/her buddy. The important factor here is giving the Autistic child the entire freedom to choose they feel comfortable and happiest with. Upon questioning the girls on how they gained the trust and love of the Autistic child, their answer was “that they just let Muzyc have her way.” This is important to gain a level of trust and cooperation. Once this trust is established, the next level will naturally fall in place.

4.2.2 Buddy to the Parent

This phase is the weaning period; where the parent understands the immense trust established and the great understanding of the buddy towards their ASD child. We are now able to implement some of the disciplinary methods needed for the child to understand and grow. So, in this period the aim of letting the Autistic child have their way is somewhat diminished, as the buddy is now collaborating with the parents to methodically state to the child that they cannot always have their way. The trust of the buddy and the child is still intact which is the most important aim of this period; but the buddy slowly introduces methods approved by the parents.

4.2.3 Parent to the ASD

This will be the consolidation period; the constant collaboration of the parent and buddy is now fully realized. The buddy can now diminish their time with the ASD child and gradually handover the child to the parents. The buddy will always be present and on hand to only act as support and be reinforcement only to the parents.

Within the church, the girls (*faifeau's* daughters) were instrumental in caring for Muzyc. It began with buddying her outside the church and gradually transitioned into the church. By this time, all three tiers were working together to establish a common goal; to bring Muzyc into the church worship and as well as themselves. This was a successful integration and allowed the girls to attend worship most of the Sundays.

This is not a proven or documented system, but it seemed to work for Muzyc and transpired to be a great help for the both of us. There were times where Muzyc was restless, and it meant in some cases to resort to moving outside the church again, with the aim of re-entering later of the service.

The method is purely on witnessing the trust Muzyc displayed towards the girls, and their attitudes towards Muzyc. Noteworthy to suggest, is the part the minister and the church played when they understood and were aware of Muzyc's ASD. This can be included in the second tier the buddy to the parents, or the church to the parents, as the church also has a role to fulfill. I believe this system within the EFKS can be explored and improved on. It is not a one fix all, but it can be a steppingstone to further improve the level of awareness, acceptance, and in turn the well- being of the ASD child.

Chapter Five

Conclusion

As I started with hope, so it is most appropriate I conclude with hope. A realization that this be likened to a small pebble being dropped in a clear calm lake, and the ripples of hope carry it far and wide. My attempts to highlight ASD as a personal journey has come full circle: as a father, as a Christian, as a theological student, and as a father. I have purposely written father twice, as one who was naive and ignorant to one who understands. A dispensation of personal reflection of physical, mental, oral, and written. It is now complete, with words that cannot be expressed but only spirit held as love and deep satisfaction, a sigh, not of despair or relief but of determination, love and hope.

As a result of my findings through my research, it is clear that there is a need to fill the gap of knowledge about ASD within our EFKS communities, here in Samoa and abroad. But before this can be accomplished, it is important that parents of children, who are diagnosed with ASD, acknowledge and accept the diagnosis of ASD. Just as we experienced with Muzyc in the beginning of our journey, the sense of denial, self- blame, guilt and not knowing how to go about getting an assessment to determine an official ASD diagnosis, was the unknown for us as parents. It is ideal to not assume an individual or child to have ASD, as it creates many levels of speculation with many unanswered questions. We can all meet a level of understanding for our children and their needs, because our love for our children is paramount regardless of having ASD or not. Love initiates hope. With that said, whatever difficulties and hardships we face with raising our children with ASD, love and hope becomes a source of therapy for many families. In turn, the experience of being an ASD parent, is indeed a blessing in disguise. For families who may suspect that a child or loved one who may have ASD, with a wealth of information, resources, and assistance available. In Samoa, an official assessment for diagnosing ASD can be completed at SENESE. For Samoans living abroad all enquires can be referred to your local General Practitioner (G.P).

Time plays a vital role in raising the awareness level especially within the context of church. As documented through my findings within the EFKS along with my personal experience, the parent ASD children act as advocates for. They become a huge influence in initiating and raising the level of awareness amongst their EFKS communities. ASD children/individuals perform everyday tasks through following a routine. It was important for us as parents to prepare Muzyc to transition from her home environment to a new environment the *falesa* (church). Parents of ASD children must collaborate with their EFKS church community and leaders. This ensures that an ASD child would be inclusive in all aspects of church life especially worship. Through patience and understanding, the roles of the EFKS church community/leader and ASD parents can be maximised effectively to nurture, protect and help the growth of spiritual learning for the ASD individual/child.

The hope is that ASD will have its own name and identity. Not be brimmed with other ailments, and that it will stand alone not relying on cultural or religious intentions. May be Samoan churches will be built with soundproof windows. Or the hope is there will be no need for any evasive action of any sort. As all and everybody will be fully educated and aware, of what and how to act with any person/child who has ASD. Within it, a hope not for them to better themselves or cladded in uniform for us, but a hope for us to better ourselves for them.

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