December 2015

Trying Times: Disability, Activism, and Education in Samoa, 1970-1980

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Abstract

In the 1970s and 1980s, Samoan women organizers established Aoga Fiamalamalama and Loto Taumafai, which were educational institutions in Samoa, an island in the Pacific. Establishing these schools for students with intellectual and physical disabilities, excluded from attending formal schools based on the misconception that they were "uneducable". In this project, I seek to understand how parent advocates, allies, teachers, women organizers, women with disabilities, and former students of these schools understood disability, illness, inclusive education, and community organizing. Through interviews and analysis of archival documents, stories, cultural myths, legends related to people with disabilities, pamphlets, and newspaper media, I examine how disability advocates and people with disabilities interact with educational and cultural discourses to shape programs for the empowerment of people with disabilities. I argue that the notions of ma’i (sickness), activism, and disability inform the Samoan context, and by understanding, their influence on human rights and educational policies can inform our biased attitudes on ableism and normalcy.
TRYING TIMES: DISABILITY, ACTIVISM, AND EDUCATION
IN SAMOA, 1970-1980

by

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Dissertation
Submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy in Special Education.

Syracuse University
December 2015
For Charles Taulapapa Anesi
Acknowledgements

It takes a village to finish a dissertation and this one is no different. I am indebted to so many people whom I have crossed paths with in my life, and for that reason I have become a better person. My utmost gratitude goes to the women organizers and the participants who generously trusted me to tell their stories. This research project was possible because of the participants’ generosity. Thank you. This project took ten years to develop and eventually evolved into this dissertation project. I would be remised to not mention the numerous founding members of Aoga Fiamalamalama and Loto Taumafai Schools who are no longer with us. To them, wherever you are in this universe, thank you for the work you have done to change the school system for all students in Samoa. Thank you to Leta’a Dan Devoe and Sharon Suhren for your current leadership at Loto Taumafai and Aoga Fiamalamalama.

I would like to thank my dissertation committee members: Professors Beth Ferri, Vivian May and Fata Simanu for guiding and challenging me to be a better writer and critical thinker. Beth, Vivian, and Fata’s support have been the wind beneath my wings and I can only soar high in the sky from here. In addition, I would like to thank Steven J. Taylor, another committee member, who departed this world too soon; thank you Steve for your leadership and scholar-activism. And especially for welcoming everyone at the beginning of the school year with an amazing barbeque. I hope my work will be reflective of your mentorship. More importantly, I am so grateful to my committee for continuously inspiring me to do social justice work.

In California: I am so blessed to have an influential and motivating group of individuals who have all played a role in my development as a person and scholar. Thank you Grace Hong, Valerie Matsumoto, Mishuana Goeman, Michelle Erai, Setsu Shigematsu, and Lucy Burns, for
sharing your alofa (love) and mana (power) with me. I am motivated by your generosity, decolonizing scholarship, and solidarity politics. To the Revolutionary Women’s Writing group at UCLA, Pua Warren, Marilu Medrano, Yvette Martinez-Vu, Isabel Gomez, Sandra Ruiz, Carolina Beltran, and Kim Mack; thank you for our check-in sessions and support in keeping it real! Thank you to my writing partners, Hayley Cavino and Ester Trujillo for keeping me motivated and accountable to my writing deadlines. Additionally, thank you to Jacqueline Elam for helping me revise earlier drafts of this project. I would also like to thank my close friends Eileen Carolipio, Sharon Steigh, Manjari Patel, Yenny Moreno, Aniko Calzadilla, Suzie Scambia, Nicole Roloff, Natalie Macpherson, and Sanja Du Plessis for keeping me grounded and determined to finish school. To my friends and mentors, Kathy and David Hanlon, thank you for your endless aloha and support. Vince Diaz and Tina DeLisle, thank you for your friendship and mentoring. Everyone has been a part of my village of alofa and I am so appreciative of your scholarships, friendships, and leadership in our communities.

In Australia: I would like to thank Professors Margaret Jolly, Katerina Teaiwa, and Kathy Lepani for hosting me as a research affiliate at the Australia National University (ANU). Thank you to Nick Mortimer for arranging my stay and research access. The ANU Pacific Collections served as some of the archival research, with the generous assistance from the folks there. Thank you for the laughs, stories, and writing sessions.

In Samoa: Gele, I hope this story gets your dancing seal of approval. I would like to thank Stella MacKenzie for trusting me to tell this story. Because of you, I was granted access into this world of advocacy, fearlessness, and transformation. I would also like to thank Lisi Anesi, and Noa and Tony Aiono for hosting me during my stays in Samoa. Doing Zumba workouts, going to BINGO, and eating yummy food nurtured my soul. I also want to give a
shout-out to my nephew and niece Jamie and Ina Aiono, my informative research team. They often accompanied me to my interviews and meetings, and taught me the research skills of talking story, doing “psychic” observation, and interviewing, all at the same time. My cousins Taulapapa Brenda and Matafeo George Latu were instrumental in locating and connecting me with the participants of this study. Thank you to Julie and George Tuiletufuga for your support for this project and advocacy in the disability community. Lastly, I would like to thank my cousins: the Anesi clan, the Carter fanau, the Fruean, the MacKenzie, and the Slavens who all physically and spiritually contributed to my comfort during the research of this project. Fa’afetai tele lava (thank you).

In Syracuse: I would like to thank my classmates and friends who made this experience fun and intellectually stimulating over the years. I am so excited to continue the next journey of our academic careers. Thank you to D.L. Adams, Liat Ben-Moshe, Jessica Bacon, Fernanda Orsati, Eun Young Kim, Heidi Pitzer, Sherry Williams, Kate McLaughlin, Jennifer Nixon, Melissa Smith, Kelli Szott, Ashley Taylor, Lauren Shallish, Kristin Goble, Carrie Rood, Casey Reutemann, Danielle Cowley, and Zosha Stuckey. Dr. Pat Stith, my remarkable mentor, and the MGSOP group for your constant support and sharing of information. Regina Jones, my Oneida aunty, in the Native Student Program who energized my passion for indigenous issues. Thank you to Silvio Torres-Sailant for checking on my progress throughout the years. Finally, thank you to the amazing department staff members who make things happen everyday: Cyndi Colavita, Rachael Zubal-Ruggieri, Mary Ann Barker, Jeanne Schmidt, Maithreyee Dube, and Michelle Mondo. You all rock!

Thank you to my parents, Charles Taulapapa and Alice Victoria Anesi, I would not be here today if it were not for your sacrifices and love. We moved across the Pacific Ocean from
Samoa so that my siblings and I can have the opportunities we have today. My mother took on the challenging task of raising five young adults, when my father passed away in 1991. She never wavered from inspiring us to be loving and respectful toward others, and to build communities that the next generations can benefit from. My siblings Monaheni, Stella, Alalatoa Wyclif, and Charles Kayl and their partners, Mona, Kennie, Leilua, and Susan, have all contributed to my academic career emotionally, spiritually, monetarily, and always allowed the storage of my “junk” in their homes over the years. For a long time, the running joke in my family has been about my endless status as a student, followed by the phrase, “The word of the day is J-O-B.” Well, all good gigs come to an end and I will find a job! To my nephews and nieces: Trevor, Manasseh, Tristan, Kennie Jr., Kim, Corey, Emily, Makaelah, Avery, and Charly, I hope one day you will be inspired to tell our stories as agents of change! To my family in Guam: John, Bobbie, Chris, Jacob, and Uncle Tony--thank you for your love and support. Thank you to my family in Honolulu: the Aninzo, Lujan, and Respall families for always hosting me when I pass through.

Lastly, Si’ Yu’us’ Ma’ase (thank you) to Keith Camacho, who’s love and support has sustained me through this project. Thank you for your patience, poignant remarks, delicious cooking, and willingness to endure my absence in our lives throughout the completion of this project. Needless to say, your island-style humor and constructive feedback has contributed to the improvement of this project. Fa’afetai tele lava.
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Chapter 1

Introduction

In 2007, my Nana on my father’s side was turning 90 years old and my brother Alalatoa and I traveled to Samoa, an independent state in the Pacific Islands to celebrate. We were representing our family from California at a mini reunion with relatives from Australia and New Zealand. It was an exciting time filled with food, laughter, and reconnections. It was a time of endless story telling, mending frayed relationships, and attending church services. Stories flowed into the wee-hours of the morning.

I remember my Aunty Sina reminiscing about the times when we were children going to family picnics around the island. She remembered her son Gele who had Down’s syndrome and passed away in 1990 at the age of seventeen. These were bittersweet moments remembering Gele and how much we missed his antics at our family gatherings. Gele loved entertaining the whole family with break dancing and singing to Michael Jackson’s entire album, Thriller. If anyone visited the house while the “entertainment” was going on, he made sure the visitor paid attention to his unforgettable show, which often times ended with him mooning the audience. Hence the joke in my family, “A fa’apea uma muli o moa, ka le ko’e fia ‘ai moa,” [If all chicken bums look like that, I don’t want to eat chicken anymore.]

In 1976, the country of Samoa still had the word “Western” attached to it, and had the colonial label, Western Samoa. Since its introduction by the German and New Zealand administrations in the first half of the twentieth century, there had been no formal schooling for students with intellectual and physical disabilities until the 1970s. Yet, there was already a place of learning outside of the home (the pastor’s school), where all the village children, including
those with disabilities, were welcomed. However, the pastor’s school was not considered to be formal education in spite of the fact that grade levels were organized from birth to sixth grade, and students were taught reading, writing, arithmetic, and biblical geography by the pastor and his wife. Student testing occurred at every level except for the babies and toddlers. The curriculum also included Western-styled sewing for the girls. One can surmise that in the pastor’s school such a lack of inclusion of people with disabilities in formal education mirrored western society and their perspectives on such populations. Gele was three years old, potty trained, and wanted to attend school like his older brother. As did most curious toddlers whose older siblings went to school, he asked his Mom, “Why can’t I go to school like Jay?”

**Purpose**

Simple, though perceptive, Gele’s astute question propelled the community to organize and establish two schools, Aoga Fiamalamalama and Loto Taumafai. The purpose of this study was to understand better the foundational and evolving perspectives of disability from an indigenous community in the Pacific Islands countries. In addition, these interdisciplinary lenses have been imperative to understanding power relationships among cultures, institutions, and policies on the local and global realms during this journey of knowledge production, storytelling, and representation. An in-depth discussion of these topics follows in the next chapter. The goals therefore of this dissertation were to examine the roles of the community members who organized these two schools for students with intellectual and physical disabilities in Samoa in the 1970s and 1980s, at a time when Samoa was still called Western Samoa and had been

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1 The London Missionary Society (LMS), currently the Congregational Christian Church of (American) Samoa started such schools for school-aged children. However, not all the Christian denominations established schools.
independent from New Zealand colonization for three decades.\(^2\) Obviously, Gele’s simple question provided more reason to keep interrogating the ableist and normative structures which shaped the ideologies of the social and educational institutions across the globe; more significantly, it motivated ongoing transformations of the Samoan community’s views about the meanings of education, disability, and medical services. Such interrogation also resonated with parents and community members, who, during this period, brought their children with various disabilities to attend school in spite of their rejection. This group of people eventually came together to challenge and change the usual answers to questions such as, “Who is educable?;” “Who deserves to be educated?;” and “How can a society that values and fosters inclusiveness transform its normative and ableist structures to include all its citizens?”

**Problem Statement**

The broader issue that gave rise to this project was that the disabled community, locally and globally, remained excluded from full participation in most societies due to limited resources, programs, and services. At the very core of this exclusion were negative attitudes, which positioned people with disabilities as “broken” (Kluth, 2006) or in need of “fixing” (Clare, 1999). Therefore, research findings and the scanty literature on education for indigenous people with disabilities offer some insights into how one group of activists collaborated to transform

\(^2\) The Samoan islands were divided between the United States of America and Germany when the Berlin Treaty was signed in 1899. In 1900, the islands of ‘Upolu, Savai‘i, Manono, and Apolima were labeled Western Samoa under German rule, while Ta’u, Ofu, Olosega, Tutuila, and Aunu’u became Eastern Samoa and later renamed as American Samoa, a territory of the USA.
institutions, structures, and peoples’ ableist perceptions of education, disability, and ma’i (sickness) in a society that was exclusive and inclusive.

The women organizers navigated normative structures of culture (Smith, 1999), gender (Tupuola, 2000), education (Tufue-Dolgoy, 2010), and disability rights and policy (Krieger, 2003). Aoga Fiamalamalama and Loto Taumafai were NGOs established because of the exclusion of people with disabilities from public and private schools. These schools illustrate the types of institutional changes that emerged (or failed to materialize) for disabled people through legislation, community involvement, and parental activism.

The study shows how the founders and organizers of Aoga Fiamalamalama and Loto Taumafai navigated the social, cultural, and political tensions in advocating for the inclusion of students with disabilities in educational and cultural institutions. In examining the roles of the community members who organized the two schools for students with intellectual and physical disabilities, this dissertation unearths the entangled story of advocacy and the fluid definitions of inclusion and exclusion. In addition, the motivation to provide an education for all, struggles within educational reforms, and the community organizing that led to the development of two schools in the 1970s and 1980s. Their stories illustrate how a small group of people can collectively shift exclusive paradigms within the education system, despite the dominant ideologies that people with disabilities are supposedly “uneducable” (Davis, 2006).

In this chapter, I first describe the background and context for this study, establish the research questions, and state the problem. Second, I provide a summary of my research methods and my own positioning in relation to the topic and context of the study. The rest of the chapter

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footnote: Hereafter also referred to as “Fiamalamalama” as this was the common name used by the women organizers. The terms “Aoga Fiamalamalama” and “Fiamalamalama” are interchanged throughout the study.
lays out my theoretical orientation and scholarly frameworks within and against which I ground this work. At the end of this chapter, I outline the remaining chapters to give the reader a sense of continuity.

**Background and Context**

The introduction of disability services to the Pacific Island countries occurred between the 1960s and 1980s (Macanawai, 2009). The initial drive evidently came from church groups, civil rights organizations, and nongovernment organizations (NGOs). Aoga Fiamalamalama and Loto Taumafai Schools are examples of such a drive for disabled people in Samoa. Thus, the years 1970 to 1980 were exciting albeit contentious times of restructuring the public education system in Samoa, after it had gained independence from New Zealand in 1962. It was during this period that education became an important vehicle for decolonization: making reforms to the curriculum, instituting graduation requirements, and initiating bilingual (English and Samoan) instruction across grade levels. Unfortunately, such reform efforts in the first fifty years of independence completely left out family and community initiatives to serve the populations with disabilities such as the two schools as locus of this study. It is of a tributary nature then that I share here the role of women’s groups, women with disabilities, and their allies, in creating the schools, and argue that the creation of these two schools was a radical and political act of

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4 For a synopsis of changes in education policy and practice since 1962, see chapter V, Aspects of Social Development by Dr. Karoline Afamasaga-Fuata’i, Gatoloaifa’ana Tilinamua, Epenesa Esea, Talalelei Eseta Fa’afeu-Hope, Lina Tone Schuster Luagalau Eteuati Foisaga Shon, and Apulu Lance Polu, in Samoa’s Journey 1962 – 2012: Aspects of History, Wellington: Victoria University Press, Wellington, and the National University of Samoa, Apia, Samoa, pp. 141-56. Ironically, though unsurprisingly, there is no mention of the efforts to serve students with disability in this chapter or anywhere else in this publication for that matter.
resistance against ableist and normative structures in education, culture, and medicine. This study then is also a significant contribution to academic studies on certain aspects of social development.

The central concern of this project is how this diverse group of women came to understand, critique, and further institutionalize ma’i, Samoan notions of illness, otherwise interpreted as “disability” in English-language educational theories and policies. Furthermore, it is important to acknowledge that some of the core founders were men, who have unfortunately passed away. According to the women, two of the founding members were the husbands and fathers of children with mental and intellectual disabilities. They played a significant supportive role to the women’s effort. They used their expertise in law and medicine to support the formalization of the organizations.

Nonetheless, this dissertation is a story told from the perspective of the organizing women; their unprecedented dissension evidently led to the organization of schools for people with disabilities. This was an important political move by and for women and advocates for social justice who have often faced discrimination and oppression, which I would argue, men seldom have had to confront. Curiously then, one asks, When did ma’i (sickness) become a

disability in Samoa and for what purpose? What was the relationship between ma’i and disability in this situation? Moreover, if notions of ma’i, activism, and disability all informed the Samoan context, then how did participants individually and collectively negotiate, and understand their own influence on human rights and educational policies in Pacific Island countries? What were the competing definitions of disability and illness operating and how did they influence the creation of the two schools? Examining these questions, I maintain, will broaden our understanding of the multidirectional, layered, and oppressive discourses of power that reinforce normalcy and marginalize people with disabilities in Samoa.

**Research Objectives and Questions**

The research questions that provided focus to this study include:

1. What were the experiences of the disability advocates and former students of the two schools during the 1970s?
2. How did the disability community and its allies approach disability as a critical lens to navigate strategically educational policies?
3. What were the paradoxes and constraints of collective community activist strategies?
4. What were the Samoan notions of ma’i, education, and inclusion operating at this time and how did these impact the education of students with disabilities?
5. What factors influenced the social and power relations within these communities?

These research questions informed my methodological and analytical decisions for this study. To get a better understanding of these research questions, I first delved into prior research on education in Samoa. Specifically, I intended to study why and how disability advocates and
the disability community merged their interests to empower disabled people in the Aoga Fiamalamalama and Loto Taumafai Schools. For this study, the terms “disability community” or “disability advocates” are in reference to people with disabilities especially women with disabilities, family members and friends of people with disabilities, medical and law professionals, educators, and community members (business owners, airline pilots, church members, and diplomats) who all played a role in supporting the disability community.

Methods

The multidisciplinary approach I used in this study revealed the complexities of the realms of disability, culture, religion, and inclusion studies. Drawing on these multiple lenses, my analysis enacts and theorizes experiences, storytelling, and memory as central in the production of knowledge of resistance and as a basis from which to challenge dominant frameworks of struggles for greater inclusion and advocacy. Conscious of various forms of subjugation, disability scholars (scholars and activists with/without disabilities) have evidently struggled to claim space, voice, and power to disrupt normative ideals of the social world that have historically ignored disabled people in the global South, US, and Oceania (Erevelles, 2011). For so long, critical education theories have ignored disabled indigenous people as knowers or critical agents of change. As Sangtin Writers and Nagar (2006) have noted, and I agree, the big challenge therefore to social institutions is to recognize the need for a deep “critique of colonialist discourses of development linked to donor-driven non-governmental organization (NGO) projects of empowerment in the Third World/South” (p. ix).6. The study also focuses on

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6 Playing with Fire (2006) is written in the collective voice of seven Indian women employed by a large non-governmental organization (NGO) as activists in their communities. The stories are based on diaries, interviews, and
NGOs as organizations reflecting social hierarchies while attempting to change them. More importantly, these stories offer insights into the process of women’s empowerment and accountability in knowledge production; a perceptive example that scholarships in Disability Studies can follow.

By exploring the stories of Samoan women organizers, I discovered that their roles as community activists and advocates were not limited to the traditional roles of aunties, mothers, and sisters, but also as agents of change within and beyond the community. Their work proved that women’s work, mother’s work, and advocacy for marginal communities could be sites of radical alliances and community change. Their advocacy revealed that normative ideas about gender roles were limited. They worked against dominant assumptions that disabled people were valea (stupid) and that Samoan women relegated only to the domestic sphere. Ethnographic findings and critiques of the critical disability, feminist, and indigenous scholarships situated my project in ways that enabled me to highlight the workings of ableism, gender, normality, and disability as signifiers of power relationships within the social structures of Samoan and U.S. Societies.

I had initial contacts with 30 participants affiliated with the schools and 4 declined to participate in the study. Of the remaining 26, 18 of those interviews were audiotaped while eight participants elected to not be audiotaped during the interview sessions. The criterion used for conversations among them about labor and politics through the lives of the women. Together their personal stories reveal larger themes and questions of sexism, casteism, and communalism, and an astounding picture emerges of how NGOs both cultivate and restrict local struggles for solidarity (Sangtin Writers Collective and Richa Nagar. Minneapolis: University of Minnesota Press).
selecting participants was that they had to be associated with the schools as founding members, former students, educators, board members, community allies, and/or parents of children with disabilities. Audio recorded in-depth interviews, participant observations, and participant reflections were the primary methods of data collection, in addition to the collection of archival, governmental, and media documents from public libraries and university research collections.

One of the core-founding members of the two schools helped me to select participants to be interviewed, and as a result, a snowball sampling technique was used (Bogdan & Biklen, 2007). As a snowball sample supports the researcher’s collection of data on a few members of the target population, then ask those individuals to provide information needed to locate other members of that population whom they know. This core member was the first person interviewed and she recommended other people involved in organizing the schools. None of the real names of the participants were used in the study except for four participants who requested that I use their real names. Verbatim interview transcripts were sent to the participants for feedback. All data were then analyzed using ethnographic methods and grounded theory of analysis. An ethnographic methods approach is about learning the social and cultural life of communities, institutions, and other settings; then, reinforces the idea that we must first discover what people actually do and their reasons for doing it before we can assign interpretations to their actions (Geertz, 1973). Likewise, Grounded Theory is a research tool that enables a researcher to seek out and conceptualize the underlying social patterns and structures of your area of interest through the process of constant comparison. Initially, researchers use an inductive approach to generate applicable codes from your data, later your developing theory will suggest to you where to collect data and more-focused questions to ask (Glaser and Strauss, 1967). I identified several core emerging themes such as the need to start schools, the organizing
process, the hopes, and goals of the founders, and the role of international aid in sustaining educational institutions in the Pacific. To validate the findings, I offered the opportunity to all of the participants to read the primary claims and to give feedback. I discuss my methodology in more depth in Chapter 3.

**Researcher’s Position in the Study**

My interest in studying family advocacy for people with disabilities was initially sparked by a previous research project in American Samoa where I worked with high school teachers on how to incorporate assistive technology into their teaching. Our family reunion subsequently enhanced this interest particularly since Gele did not live to enjoy the fruits and labor of his relatives whose courage and love resulted in significant changes in the treatment of people with disability. For Gele, his family continues his dance.

My own positionality is crucial to the implementation and analysis of this project. One important aspect of indigenous research is the need for the researcher to locate him/herself (Alcoff, 1991). Before I explain my project further, I therefore need to map out my own positionality. Simultaneously, I am a Samoan woman, daughter, cousin, niece, and educator; I am also an able-bodied person, a diasporan Samoan, a “Western” educated student, and the researcher. Importantly, this research is about my community, and I therefore have more at stake than someone from “outside” the community in this process of representation and storytelling. “Real participation,” as LeCompte and Schendul (1999) observe, “may even mean a lifetime of collaboration” (p. 15). In many ways, my involvement with Aoga Fiamalamamala and Loto Taumafai has just begun. While I think I know the community well, I recognize there is also much I do not know and never will. My reading of these school histories, and of the wider implications of their formation, is therefore partial and open to critique and debate.
Similarly, ethical considerations require careful reflection about my personal subjectivity in relation to my interview participants. I have lived off-island since I was eight years old and my position as a researcher places me as an “outsider.” As Miliann Kang (2000) explained, research conducted by scholars who are first- or second-generation immigrants of the groups they are studying is fraught with personal and professional dilemmas. In my case, I am researching an institution co-founded by my Aunty Sina. This relationship directly affects my role in the project, compelling me to balance the intertwined dynamics of family, culture, and researcher (Kang, 2000). Therefore, I have had to attend carefully to any potential class, family, generational, and political biases in collecting and interpreting data.

In addition, I found it important to integrate Pacific knowledge systems and conceptual frameworks (Gegeo, 2008). Perspectives by Pacific peoples are pivotal to representing the study in culturally appropriate ways. Fully recognizing that doing research and cultivating knowledge are about power relations, I also sought to develop strategies for more equitable forms of speaking and hearing. As Māori scholar Smith (1999) noted, decolonizing research is not simply about challenging and making refinements to research methodologies; instead, it entails a much broader and more purposeful agenda, in that decolonizing research in fact transforms the institution of research, which is historically and “inextricably linked to European imperialism and colonialism” (p. 1). Work by Alcoff (1991), Gegeo (2008) and Smith (1999) have also helped me to examine my positionality in relation to the participants and in the analysis of my data. As Maynes, Pierce and Laslett (2008) argued, “personal narrative analysis can never be disconnected from the analyst” (p. 147). Hence, in planning and carrying out this study, I examined power relationships between myself, as researcher, and my participants, as researched, to acknowledge both contextual, situated knowledge and interpretive views, and to recognize
how my own biases and personal background might influence every aspect of my study (LeCompte and Schensul, 1999).

As I started my educational journey in Disability Studies and Special Education, the idea of inclusive education and society was a familiar one, given my Pacific Islander background. In fact, the most difficult concept for me to understand was, “Why not include people with disabilities in all aspects of our society?” I assumed in my homeland of Samoa that people with disabilities were included in all contexts of society and it was difficult to recognize that people with disabilities were being “excluded” in formal schools, and within a culture that fostered inclusiveness. Historically, Samoan culture has adapted to racial inclusiveness and strongly valued collective harmony among all peoples, so it was not easy for me to confront the fact of the exclusion of people with disabilities in the context of education. Given that, schools are spaces where the production and sharing of knowledge occurs, to exclude consciously a group because of misguided perceptions of ability and intelligence is problematic. In fact, this kind of opposition to, and questioning of, exclusive practices in schools led the women organizers to establish schools for the disability community.

**Theoretical Foundations**

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Historically from the 19th century, Samoans have had a history of ‘Pacific circuitry’ that was filled with people who were not white, European, or American: it was a 'Brown Pacific,' so to speak. This circuitry included islanders from Melanesia, Tonga, Fiji, Tokelau, Gilbert Islands, Tuvalu, Rarotonga; See Salesa, D. (2003), *The New Zealand Journal of History*, 37 (2),171-188. In the early 19th century, German corporations brought Chinese indentured laborers to Samoa. In 1905, about 528 Chinese left Swatow for Samoa. In total, some 3,868 Chinese arrived between 1903 and 1913 under German Administration [Ben Featuna’i Luiua’ana, (1997 June), *Journal of Pacific History*, 32 (1), 29-48].
An interdisciplinary analytical framework that questions normalcy, ableism, and compulsory able-bodiedness that draws on indigenous notions of ma’i or sickness, has guided how I conceptualize this project. Critiques of ableism by disability studies scholars Lennard Davis (2006), Cluny and La’avasa Macpherson (1990), Robert McRuer (2006), and Fiona K. Campbell (2009) have greatly informed how I explore the body, especially the disabled body as it is situated in social, historical, economical, and political contexts. Drawing on historical materialism, Erevelles (2011) examined how the disabled body was constituted within social relations of production and consumption within transnational capitalism. Erevelles’s work theorized disability at the intersections of race, class, gender, and sexuality within the U.S. and the global contexts. More importantly, her work re-theorized disability as a materialist construct in the context of global citizenship. Campbell’s work, situated in Australia or the global South, questioned our “seduction of sameness as the basis of equality claims” (p. 4). She examined what the study of disability tells us about the production, operation, and maintenance of ableism and argues that contemporary scholarship shift away from disability to a more nuanced “exploration analysis of epistemologies and ontologies of ableism” (p. 3). Erevelles’s and Campbell’s work on transnational capitalism and the maintenance of ableism in perpetuating imperialism heavily influenced how this project is conceptualized from a decolonial lens. Disability that results from political, social, and economical factors is also relevant in understanding unequal power relations among nations, especially between nations in the northern and southern hemispheres.

Examining economic issues entwined with the politics of development and financial prosperity is relevant here. According to the United Nations, a “least developing country” is one that exhibits the lowest indicators of socioeconomic development with the lowest Human
Development Index (human capital weakness criterion) ratings of all countries in the world (United Nations Conference on Trade and Development, Vulnerability Profile of Samoa, 2006). In 2010, Samoa graduated to the status of “developing country”, which meant that the graduating country “is expected to have demonstrated, through its improved socio-economic performance, irreversible structural progress” (United Nations Conference on Trade and Development, Vulnerability Profile of Samoa, 2006, p. 3). This status meant that the country has developed a domestic saving capacity and concessionary financing of taking out low interest loans from other countries reduced in numbers. The influence of economic development policy is crucial to the discussions about how transnational capital reinforces ableist ideologies and social values. These logics also coincide with the business of education, diseases, and disabilities.

Combining the economic status of a newly independent nation with an unstable economic infrastructure, and the professionalization of education and healthcare systems complicates our understandings of disease, disability, and illnesses as defined by multinational organizations like the United Nations, the World Bank, and the World Health Organization. Moreover, an indigenous understanding of disability or sickness adds another layer to this complex equation about how communities in the Pacific define and redefine differences and embodiment. In this case, the idea that “disability is a metaphor for disease,” as the work of disability studies scholar Burton Blatt (1999) asserted, in the nature of institutions and the need for the deinstitutionalization of people with mental retardation that are perceived as sick or “deviant”. The critical work by scholars Cluny Macpherson and La’avasa Macpherson (1990), studied the Samoan practices and beliefs of contemporary indigenous healers, traced a history of Samoan indigenous medicine by showing its capacity to adapt, change, and absorb “foreign” influences. More importantly, their study juxtaposed the use of traditional Samoan medicine alongside
Western medical practices and the negotiations within these options by the community. The Macphersons’ claim that the role of the taulasea (healer) was entangled with Samoan’s beliefs about health, illness, and the nature of the human “organism” foregrounds Samoan understandings of disability and impairment.

**Logics of Ableism, Compulsory-Able-bodiedness, and Normalcy**

Understanding ableism can greatly influence understandings of how the women organizers advocated for the education of people with disabilities within normative structures such as schools and policies. Disrupting such structures can maybe then lead to more just and democratic education systems needed for students to grow and thrive. In addition, while the formation of the two schools at the center of this inquiry represents a first step toward greater inclusion and belonging for people with disabilities in Samoa, this story is about an intra-cultural critique of Samoan discriminatory attitudes toward people with disabilities and differences. This topic is difficult to broach within the community, due to diverse opinions and understandings of inclusion based on Christian values and due to my own family connections to the schools. However, I argue that in the end, the women organizers balanced cultural and social protocols in order to accomplish their goals of creating schools for the disability community.

Generally, literature in disability studies has examined the practices and production of “disablism,” a set of assumptions and practices that promote the differential or unequal treatment of people because of actual or presumed disability (Campbell, 2009). Much of the literature has focused on interrogating negative attitudes and barriers and assimilating people with disabilities into normative society. Ableism refers to “A network of beliefs, processes, and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a
diminished state of being human” (Campbell, 2009, p. 44). Disablism refers to a general disability as inherently negative and should the opportunity come, be ameliorated, cured or eliminated. Others defined ableism as an attitude that devalues or differentiates disability through equating able-bodiedness with normalcy (Ho, 2008). Some use the term ableism interchangeably with the term disablism, but Simi Linton (1998) argued for decentering abledness in order “to look at the world from the inside out” (p. 13). Using ableism as a conceptual tool can add to the transcending of procedures in structures for governing civil society. There is no consensus in the literature about what ableism entails in terms of practices and behaviors: however, what is consistent, is the argument that an ableist viewpoint on impairment or disability is inherently negative and should be “cured” or “fixed” (Kluth, 2006) or more forcefully be eliminated (Gould, 1996; Lombrado, 2008; Longmore, 2003; and Mairs, 1996).

Fiona Campbell’s (2009) naming of “The Ableist Project” shifted the gaze of contemporary scholarship away from disability to a more nuanced exploration of epistemologies and ontologies of ableism (p. 3). Campbell’s work echoed earlier work by Tom Shakespeare (1998), in which he concluded, “perhaps the maintenance of a non-disabled identity…is a more useful problem with which to be concerned; rather than interrogating the other, let us deconstruct the normality-which-is-to-be-assumed” (p. 28). Likewise, Hughes (2007) advocated persuasively for studying “pathologies of non-disablement” (p. 683).

Critiques of normalcy have similarly been central to disability studies, as illustrated by Lennard Davis’s (2006) analysis of the historical emergence of normalcy and Rosemarie Garland-Thomson’s (1996) introduction of the concept of the “normate”. The deceptive function of these concepts underscores how heterosexual and able-bodied identities are the naturalized
norm and the baseline of what is a human being. Their functions, covered over with the appearance of choice within a system in which there actually is no choice (McRuer, 2006).

In this dissertation, I use the concepts of ableism, compulsory able-bodiedness, and normalcy to analyze disability within the Pacific community. The indigenizing of ableism and normalcy in the Samoan context functions in similar ways to the US; both are contingent on the binaries of disability/ability and disabled/abled. Within the Samoan context, there is a conflation of ability with inclusion in the community and there are inconsistencies of practice between inclusion and exclusion of people with disabilities in the community. For example, in Samoa before 1980, there was the exclusion of people with disabilities from formal schools. However, in the aoga faifeau (pastor schools), they were included and held important roles, such as Sunday school teachers or as elders to the younger children. In some households, people with disabilities took on a vital role of tending to the fa’atoaga (farm), which fed a large number of people. Among the frictions that I explore in this project are tensions within and between the schools and cultural spheres around who can belong, and how people in these spaces (dis) engage with disabled people. Thus, it is difficult to make a firm argument that people with disabilities in Samoa were excluded in all realms of the community because often times they assumed an in-between position.⁸

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⁸ In the 1960s, many children with physical disabilities attended the compound schools at Malifa. As long as they could read, write, and talk, they were included. In village schools, disabled children were free to come and go as long as they did not disrupt class. Those with intellectual or cognitive disabilities also came along and quit as they reached the higher levels; at that point, families stopped them so that there was more labor for the farms and other household tasks. I think the distinction that can be made for Samoa is that as classrooms became more modernized and standardized tests controlled the curriculum, inclusion perhaps became a legal and pedagogical problem. Historically however, Samoans did not pretend that there was
Ongoing Legacies of Eugenics

Tobin Siebers (2008) suggested people with disabilities are well aware that disability is the “last frontier of unquestioned inferiority” in society (p. 6). Indeed, eugenics remains a key shaper of disability policy, thought, ideology, and practice. As Mitchell and Snyder (2006) noted, “eugenic thought… played a crucial role in defining a distinctive version of deviance that allowed physical, sensory, and cognitive differences to shadow each other--as if one could not be called into being without the others” (p. xii). In the *Mismeasure of Man* (1981), Stephen J. Gould extended the discussion of eugenics by critically examining biological determinism. He also critiqued claims that worth can be assigned to individuals and groups by measuring intelligence as a single quantity or by dubious physical markers (e.g. craniometry or the measurement of the skull). The eugenics era also pioneered techniques that managed “defects” through questionable therapies, invasive case histories, and acute surveillance techniques. These techniques turned people with disabilities, particularly those in institutions, into a readily available research pool (Mitchell & Snyder, 2001). Gould analyzed the scientific weaknesses, limitations, and political contexts of determinist arguments and criticized the myth that science is an “objective” enterprise. Instead, Gould suggested, science “must be understood as a social phenomenon, a gutsy, human enterprise, not the work of robots programmed to collect pure information” (p. 53). He questioned the validity of such measuring instruments and stated, “Science, since people must do it, is a socially embedded activity” (1981, p. 53). Gould’s inquiries about the validity and objectivity of scientific studies were important, since these areas anything wrong with the disabled; it’s just that for the intellectual disabilities, the term valea or ma’i connoted difference, hence benign neglect.
of study have historically influenced the creation of policies and the treatment of people with disabilities. For example, the representation of people with disabilities using the medical model as individuals who are inherently flawed in order to qualify for U.S. citizenship (Baynton, 2006). The focus is on the person’s disability rather than on the context, that creates disability via exclusion and inaccessibility.

Thus, although disability is often understood as a medical condition treated in the medicine, which has led to an improved quality of life for people with disabilities and improved health, it has also come at the expense of people’s freedoms and rights. The use of tools such as diagnosis, labeling, treatment, and institutionalization has been some of the ways in which society has wielded control over the lives of people with disabilities. Medicine has often relied on a deficit-model of disability and focused solely on remedial cures and interventions (Goffman, 1963; Wolfensberger, 1975). Because the medical model views disability as something “wrong” with a person, it assumes that the ultimate solution is to “cure” the person so that he or she can lead a “normal” life. The medical model did not originate in Samoa, but it, along with the more indigenous ideologies, informed many of the practices and approaches to disability.

Medical Model, Charity Model, and Social Model of Disability

Various models of disability were circulating during the time of the study in Samoa. Along with Western and indigenous cultural influences, these models of disability informed both the meanings of disability, but also the approaches to services. People with disabilities share an intertwined history between the medical model to restore normalcy, and the eugenics movement
to make the human race “perfect” by eliminating people with undesirable characteristics from the population. The difficulty with many curative/remedial medical practices is that they foster overt and covert eugenic ideologies and various means of controlling reproductive rights or social sanctions, which eliminate certain peoples from the population (Linton, Mello, & O’Neill, 1995). A dominant perspective within the medical model is that society does not need to change, while the individual with a disability must. Hence, as historian Paul Longmore (2003) explained, “the medical model remains the typical perspective not only in medicine, rehabilitation, special education, and other applied fields, but in social sciences and humanities as well” (p. 3).

The charity model of disability represents people with disabilities as pitiful and in need of nondisabled peoples’ assistance. A widely known example of the charity model would be telethons, such as the Jerry Lewis Telethons for Muscular Dystrophy. The assumption behind the telethon is that all people with disabilities want to be “fixed” and are in need of charity rather than autonomy, choice, or rights. Another misconception by people supporting the charity model is that people with disabilities do not contribute to society and therefore must be cared for. Such assumptions reinforce discrimination, prejudice, and stigma experienced by disabled individuals.

In connection to education, eugenic ideologies of biological inferiority play out in Special Education services as students are tracked, placed in self-contained classrooms, and excluded from school cultures based on their perceived (in) ability to conform to ableist values and expectations. These values narrowly define school success as something solely based on standardized, high-stakes test scores. The intersectional role of economics, class, and inequality all “reward” high-performers with more funding while simultaneously “punishing” low-performers with less funding allocated to such schools. Such “band-aid” laws marginalize and stigmatize students with disabilities, second language learners, and students of color who become
the scapegoats for low-test scores and an outdated school system (Noguera, 2008; Harry & Klingner, 2006).

A more recent model of disability is the social model of disability. This model positions itself in direct contestation to earlier medical and deficit models of disability. In contrast to the medical and charity models of disability, the social model of disability based on experiences, views, and practices, which include people with disabilities in multifaceted aspects of decision-making that concern their lives (Kluth, 2006). As Longmore and Umansky (2001) stated, a sociopolitical or minority-group approach to disability, investigated the relationships between meanings attributed to particular bodies and the organization of power in society. This means that an investigation of the body can illuminate its complexities, its politics, its lived experience, and its relation to subjectivity and identity (Wendell, 2006).

By understanding the body and the institutions that define and redefine it, a more inclusive understanding of disability can emerge. I would argue that to sufficiently articulate a social model of disability requires that the examination of the local context as an important site of meaning. This study differs from previous scholarships in the Pacific region due to its geopolitical/social locations and its focus on women’s leadership roles in the education system. It also provides a much-needed expansion of disability frameworks, which largely focused on Western contexts and perspectives. Additionally, studies on indigenous women and people with disabilities rarely represented them as agents of change and as experts about their lives and cultures. By focusing on disability in Samoa from 1970-1980, this work also adds much-needed nuance to common themes within disability studies, such as the influence of eugenics, institutions, cultural knowledge, colonialism and educational policies. Finally, I contend that
naming ideologies of ableism and normalcy within the Samoan context will bring transformative policies and attitudes.

**Decoloniality**

Education in Samoa was an important vehicle for decolonization; as such, the decades following independence in 1962 entailed restructuring the education system. Reforms made to curriculum, stricter graduation requirements, and the initiation of bilingual (English and Samoan) instruction across grade levels were among the changes. In addition, equally interwoven into the curriculum taught in schools, knowledge systems and conceptual frameworks are the Pacific Islanders’ understandings of culture and knowledge production systems (Gegeo, 2008). As Māori scholar, Smith (1999) noted decolonizing research aimed at transforming the institution of research is historically and “inextricably linked to European imperialism and colonialism” (p. 1). Moreover, decolonial effort makes the historical dialogue necessary because foregrounding ancestral relationship to place and the decoupling of nature and history has helped to mystify colonialism’s history of forced migration, suffering, and human violence (DeLoughrey & Handley, 2011).

To contest colonialist legacies, for instance, Māori researchers have paid attention to the negative impact of colonial education systems on forms of knowledge associated with holistic health/well-being and positive gender relationships for whānau (Pihama, Cram, & Walker, 2002; Simon & Smith, 2001; Smith, 1999). As Albert Wendt suggested in his foreword to Sue ‘su ’e Manogi (2009), all the speeches, lectures, and writings by the Samoan Head of State, His Highness Tui Atua Tupua Tamasese Ta’isi Efi, revealed attempts “to persuasively elucidate those ways [Samoan indigenous ways of self, being, seeing, thinking, and becoming to cope with modernity] and help decolonise ourselves and restore our pride and self respect” (Suaalii-Sauni,
Tuagalu, Kirifi-Alai, & Fuamata, 2009, p. ix). Tui Atua argued that there are indigenous forms of self and ways of being and thinking in Samoa that can be used to cope with the present and to envision future paths.

Decolonizing projects also contest the dominance of the global North with regard to universalizing and totalizing tendencies, even in critical writings about disability, which have resulted in marginalizing knowledges and lived experiences from the global South (Meekosha, 2011). Meekosha contends that a southern theory of disability that challenges hegemonic values and concepts embedded in contemporary disability studies must include an analysis of the “lasting disabling impact of colonialism” (p. 667). Thus, this project is more than about documenting historical knowledge: it is also about healing and re-shaping our imaginations with regard to the significance of Samoan women’s role in history and education.

**Feminist Disability Theory**

To understand better the intersecting complexities of these reflections and stories, I also build on the work of feminist disability scholars who reminded us of the cultural history of the body, which is fluid and interdependent. Increasingly through the women’s advocacy, the work of feminist disability scholars also resonates with the themes of identity, representation, space, history, and neo-colonialism. Scholars such as Rosemarie Garland-Thomson (2006) and Simi Linton (2006) remind us that it is a mistake to think that the complexity of disability experiences and identities can be understood independent of other aspects of our lives (O’Toole, 2004). Feminist disability approaches also fostered complex understandings of the cultural history of the body. It goes beyond explicit disability topics such as illness, health, beauty, genetics, eugenics,
aging, reproductive technologies, prosthetics, and access issues (Snyder, Brueggmann, and Garland-Thomson, 2003). Anita Ghai (2003), a disabled scholar from India, stated that in order for feminists and disability theorists to explore disabled women’s issues, we need a radical reworking of the way we approach the disabled body and its roles in society. She urged the importance of analyzing the disabled body as a social and material category that is not only defined as “either/or” but also as “both/and” (p. 112). Ghai contended that it is not necessary to force a choice between corporeal essentialism and social oppression. The disability rights movement (DRM), for example, tends to erase the body, and the social model approach is reluctant to talk about the impaired body (Ghai, 2003). Both sides of the debate make important points that influenced the social construction of disability and illness. The activists in the disability movement (mostly male veterans) were equally reluctant to include bodies in their fight for rights. Ghai argued that it is counterproductive to homogenize differences that exist between categories of disabled women, and not to treat critical factors such as ethnicity and disability as unitary.

**Parent Advocacy**

Partnerships between families and educational professionals have been identified as critical in providing effective educational services to students with disabilities (Colaruss & O’Rourke, 2007; Freiberg, 2006). While parent organizations began locally, over time they also realized the value in organizing at the national and international levels (Dybwad, 1983). Beginning in the 1960s, parent organizations began to collaborate across disabilities. For example, members of organizations such as The Arc (formerly known as the American Association for Retarded Citizens), the Autism Society of America, and the Cerebral Palsy Organization began to collaborate and coordinate activities together (Leiter, 2004). In the U.S.
context, many of the battles that parents fought on behalf of their children during the 1960s and 1970s centered on public education for children with disabilities. The political struggles to acquire rights and mechanisms to ensure the inclusion of people with disabilities, especially in schools, often run the course of first parents obtained civil rights for their children in the form of privileges to community-based programs; and later rights used as a device to regulate relationships with professionals who provide the services (Leiter, 2004). Similarly, parents in Samoa also emulated such strategies by creating formal organizations as solutions to their problems with social services. Hence, the role of parental activism in creating policies and mandates that include children with disabilities in schools cannot be understated. Parents want the best for their children and for professionals to recognize that they play a key role in caring for their children. Thus, this study must consider the inclusion of families of children with disabilities, precisely because they have been at the forefront of seeking equality and justice.

Rationale and Significance

Although this is a Samoan story, it contains critical lessons for other indigenous and minoritized communities, and for those who study or create policy with and for them. More importantly, this story points to the possibilities and struggles inherent in indigenous education. My goal is that understanding this story will prompt social action and a more expansive fulfillment of the vision of social justice upon which Aoga Fiamalamalama and Loto Taumafai were first created. The broader relevance of this study is an inquiry into the larger struggle for self-determination by indigenous communities, raising issues of identity, inclusion, access, and community empowerment. In addition, this study forces us to engage in the topics about the marginalization of indigenous women, women with disabilities, and why sharing their experiences and politics in publication and literature can create dialogue and transformative
action. The idea that their knowledge and experiences are worth learning and knowing is a contribution that activists, community members, and scholars in the fields of Disability Studies, Inclusive Education, Native Studies, Women, and Gender Studies can benefit from.

Furthermore, I engage with debates in disability studies, anthropology, and education as to what “otherness” as a topic of study, means in terms of indigenous communities of Samoa. Existing research in the social sciences and humanities tends to analyze how dominant ideas and institutions cast disabled people (Davis, 2006) and the “sick” as “others”. Yet, anthropologists, educators, and historians have not studied Samoan constructions of disabled Samoans as “others”. What I mean by this is that the specific intersection of Samoan and disabled identity construction has not been studied. Instead, scholars have tended to focus on religion and sexuality (Tcherkezoff, 1987), gender (Mageo, 1998), cultural models (Shore, 1996), education (Coxon, 1999), inclusive education (Tufue-Dolgoy, 2010), language (Duranti, 1988), the mata’i or chiefly systems (Meleisea, 1987), democracy (So’o, 2008) and sexuality (Mead, 1928), among other topics. Although these scholarly works have informed my understanding of historical and contemporary Samoan society, there are no monograph-length studies about disability and the role of women activists in Samoa. Such an investigation is crucial because women have been instrumental in advocating change and making decisions in Samoan culture, yet there is little recognition of this influence. Therefore, this study is significant both as an investigation of Samoan women advocates and activists and as a study about ableist and critical beliefs about disability, culture, and ma’i (sickness) in a Samoan context. As this project showed, the intricacies of these interactions make it difficult to generalize a monolithic disability perspective across geo-political and socio-political spaces.
Lastly, the tough part about re-telling stories and oral histories is that some of the founding members of the schools, to whom I owe deep appreciations, did not live to see this project’s completion. Knowing the lives that came before and speaking of them is a great burden and responsibility; it has also been a privilege. Consequently, any failings, errors of facts, and interpretation are mine.

**Chapter Overview**

Throughout this study, I interrogated connections between notions of disability (and ableism) and normative ideologies of differences, which historically been theorized as “deviance” fixed within or on the body. I drew on the concepts of body matters, or the materiality of the body and the historical conditions that make some bodies matter more than others (Erevelles, 2011), the concept of ableism (Campbell, 2009), Samoan medical beliefs and practice (Macpherson and Macpherson, 1990), and the notion of compulsory able-bodieness (McRuer, 2006) to explore how the body is constituted. Particularly how the disabled body, is constituted within the social relations of production and consumption of transnational capitalism (Mohanty, 2006; Erevelles, 2011). I used these frameworks to analyze how concepts of ableism, disability, oral histories, colonialism, and capitalism move across borders and cultures used against marginal communities as a means of reinforcing normative structures that are perceived as orderly and appropriate.

In this introductory chapter, I have focused on the theoretical frameworks for this study. I have also included my research objectives and questions that guided this study, as well as a discussion of my own positionality. I am particularly interested in my position as a researcher who is a member of the communities involved in this study. Locating the study within the larger problem of exclusion in education illustrates how research focusing on Samoa can foster wider
social change (Fine, 1992). The focus of this story on disability in Samoa also parallels the significance of asking larger questions on equity, belonging, and citizenship at the local, domestic, and global spheres.

Chapter 2, “Historical, Cultural, and Social Contexts of Education and Disability,” provides historical, political, social, and cultural contexts that inform my analysis. The history of Samoa as a former New Zealand colony greatly influenced the educational structures and systems. Much of Samoa’s education infrastructures were identical to those of New Zealand. The entangled history of education with the country’s colonial history reflects these prior value systems. I examined the role of missionary schools in the wider education system in Samoa; and how Samoans and Pacific Islanders responded to such colonial histories.

Moreover, I examine Samoan belief systems of disability, illness, and healing, which have influenced the history of people with disability in educational institutions as one of exclusion and marginality (Lene, 2004). Before the establishment of educational institutions, such as Aoga Fiamalamalama and Loto Taumafai, many people with disabilities were isolated and kept hidden within their family homes and villages. How we understand Samoan notions of ma’i or sickness, healing and responses to human differences is therefore essential to how we do (or do not) educate students with disabilities (Valle & Connor, 2010). I examined the language of disability and Samoan understandings of ma’i (sickness). Finally, I conceptualized how the historical, cultural, and social contexts are important to consider in the development of and advocacy for the schools.

Chapter 3 addressed the methodological approaches I used to carry out this ethnographic and oral history study, especially with regard to how best to offer an emancipatory representation of “otherness” or social difference. This chapter focused specifically on the research design,
setting, data collection, and data analysis I used in carrying out this project. I used the grounded theory method for coding and analyzing my data by identifying categories and connecting them (Glaser & Strauss, 1967; Urquhart, 2012). More specifically, this method of analysis explains the process through examples, by further probing how my data is represented, by following an emerging storyline in the data, and by using the examples in my data to lead to new theory and insights. Furthermore, I explored the ethical considerations and culturally appropriate approaches considered in carrying out this research (Smith, 1999; Baba, Mahina, Williams & Nabobo-Baba, 2004). Along these lines, I also used qualitative research strategies of in-depth interviewing, together with “unstructured” or “open-ended” (Bogdan & Biklen, 2007) interviewing, to understand how the women organizers came to develop their perspectives. Collectively, these methods comprise the Talanoa research methodology, a process referred to as a conversation or talking in both formal and informal settings (Vaioleti, 2006).

Chapter 4, “The Search for Funding and Land: The Case of Aoga Fiamalamalama and Loto Taumafai Schools,” focuses on the history of non-governmental organizations (NGOs) in engaging educational institutions such as Aoga Fiamalamalama and Loto Taumafai. I evaluated the role of international aid in school development and sustainability. I examined the impact of Non-Governmental Organizations (NGOs) in developing countries, especially in the education context. The women’s advocacy is a push to think deeply about building structures of accountability and transparency in the education system. Likewise, I focused on the collaborative relationship between the preschool and women organizers in advocating for the disability community.

Stories about why these individual actors got involved in the organizing of the schools; how they negotiated the normative policies and systems within the Samoan community to fulfill
their goals of creating schools for the disabled; and finding land for the establishment of the schools was an essential discussion. All led the women organizers to independently fundraise and seek international aid. Lastly, one of the common issues that arose for both schools is that by taking funding from overseas donors, they were dependent on these funding sources in order to run the schools. In the past, some NGOs had lost their funding sources because of unmet stipulations by funders. Therefore, what are the implications for the future of the schools, especially when they are operating on temporary grant monies that only last for one fiscal year and tied to priorities of the donors?

In Chapter 5, “Early stages and planning of the schools: There was a need and we acted” examined the networking strategies and community organizing that evolved out of the founding years of Aoga Fiamalamalama and Loto Taumafai. I analyzed the stories of the founding women members, including the supportive roles played by community organizations such as the Western Samoa Society for the Intellectually Handicapped (Inc.), the New Zealand Society for the Intellectually Handicapped (Inc.), and the Loto Taumafai National School. This chapter emphasized the main actors in the organizing of the schools and their motives, aspirations, and advocacy goals. This chapter also traced the layers of gendered roles and grassroots organizing as advocacy; for example, why the women organizers understood their roles in the school’s establishment as “advocates” rather than “activists”. Thus, the stories in this study enact the process of a journey of the personal and political struggle.

In Chapter 6, “Stories of Belonging by Former Students” I delved into the perceptions of the former students of the schools. I specifically explored the stories of Sasha and Lisa, two women with disabilities, who were students of the schools; and are now staff members and disability advocates. I placed their stories in a larger context of what we know about the students
who attended these schools during the time of the study. Lastly, I discuss what the greater story of Sasha and Lisa tell us about access, ableism, and inclusion.

Finally, in Chapter 7, “Conclusion”, I revisited the research questions and objectives, which guided this study. The experiences of the disability advocates and former students in the two schools vary, however, similar exclusion and difference were common themes shared in most of the participants’ narratives. The women organizers realized that their advocacy could be effective if they received the financial support from international organizations. In some ways, international support through aid was also a critical lens to navigate strategically educational policies. What I mean by this is that the local government did not value the women’s organizing of the schools until foreign agencies required the government’s participation. The paradoxes and constraints of collective community activist strategies also informed values and discourses of the time in Samoa.

The weaving together of the wider meanings and constructions of disability by the participants in this study offer an insight into how parent advocacy, women organizers, and the disability community understood disability, ma’i, and education from a marginal position. Furthermore, I argue that the creation of these schools is an example of approaches that challenge ableist and normative structures in Samoan culture. Specifically, perceived as decolonial frameworks of resistance to the status quo and ingrained systems of oppression. Finally, this chapter explained the implication of this story, as well as my recommendations and limitations based on the results of this study.
Chapter 2

Historical, Cultural, and Social Contexts

The historical backdrop for this study begins during the transitional period in Samoa, from 1970 to 1980. As a newly independent state (from New Zealand), Samoa was coming to terms with the expansive need for social welfare programs, especially education and healthcare. As the title of this study indicates, “trying times” referred to the challenging era for people with disabilities, especially in terms of inclusion and education. People with disabilities and their allies resisted exclusion from formal schools and advocated for non-governmental organizations (NGOs) to meet their goal of attending school. Such protests by the disability community and their allies directly questioned normative and ableist structures in the education system. Certainly, the education system in Samoa inherited colonial structures of exclusion: however, the attendance of people with disabilities in formal schools slowly shifted the broader ideas about those deemed educable.

This change did not come overnight and advocacy by Samoan women, women with disabilities, community members, and their families helped forge this change. Yet, history seldom highlighted women’s advocacy efforts in school reform in Samoan history. Thus, a central aim of this project is to recover and acknowledge this history. Sadly, students with intellectual and physical disabilities in Samoa were not formally educated in schools until the establishment of Aoga Fiamalamalama and Loto Taumafai schools in 1979 and 1980.

In this chapter, I examine the historical, social, and cultural contexts of education and disability that were operating at the time of the creation of these schools. In the first section, I review the history of Samoa, which greatly influenced the history of education and educational
policies. Next, I discuss some social and cultural contexts of education and disability. Precisely, I examine fa’a Samoa (Samoan way of life), attitudes about ma’i (sickness), as well as stigmatizing language about people with disabilities. In the concluding part, I analyze the wider implications of colonial legacies on social services and on discourses of disability and ma’i.

**History of Samoa**

Attending to historical contexts is imperative for understanding the place, ideologies, and practices that shaped past and present contexts in Samoa. Samoans’ perspectives prior to European contact must be considered here, since these accounts are different models of alterity and identity, which allowed the integration of differences into the social structures of the Samoan communities (Tcherkezoff, 2004). Thus, known contact between the West and the islands are often documented through European expedition writings. For example, the Dutch explorer Roggeveen brought the first Europeans to the Islands in 1722. The French navigators Bougainville and La Perouse arrived in 1768 and 1787, respectively (Salesa, 2011). However, not much was known in the West about the island groups in central Polynesia until 1830, when the London Missionary Society (LMS) arrived in the village of Sapapalii in Savai’i, another island in the Samoan archipelago. Thus, the history of mission work in Samoa by the LMS cannot be separated from the history of education.

At this time, political and commercial interests by Great Britain, Germany, and the U.S. were also on the horizon. Under German rule, LMS missionaries welcomed the establishment of a settled government by the 1900s (Meleisea, 1987). The German government kept their promise not to disturb the work of the LMS and left the “business” of education entirely to the different missions, including the LMS, the Methodists, Roman Catholics, the Latter Day Saints, and the Seventh Day Adventists (Coxon, 2007). Thus, the education system was greatly
influenced by the following: (a) Christian mission schools in the 19\textsuperscript{th} century (Lameta, 2005); (b) 20\textsuperscript{th} century colonial governance of the islands by Germany (1900-1914) and New Zealand (1914-1962) administrations (Meleisea, 1987); and (c) After 1962, post-independence struggles by Samoan leaders to continue the colonial education system (Dolgoy, 2010, p. 63).

In the late 1800s, the German, American, and British commissions were economically invested in copra and cacao plantations and in shipping ports. As a tripartite government, there existed three powers over a group of small islands. Germany, the United States, and Britain generally allied with opposing chiefly factions, which often fueled civil unrest (Meleisea, 1987). Disputes among the three powers and the local Samoans never seemed to end. The Treaty of Berlin in 1889,\textsuperscript{9} for example, divided the Samoan islands into two halves: the eastern and western islands. Thus, outsiders separated the islands, not Samoans themselves.

The United States and Germany split the Samoan archipelago into two regions, each with separate political systems. Germany took over Samoa from Britain, in exchange for recognizing British interests in other parts of Africa and the Pacific (Field, 1991). The eastern islands were under U.S. rule and consisted of Aunu’u, Manua, Ofu, Olosega, Ta’u, and Tutuila. These islands known as “American Samoa” and considered an unincorporated territory of the US. The western islands became a German protectorate, comprised of Apolima, Manono, Savai’i, and Upolu (Fairbairn-Dunlop, 1998). These islands were under separate German and New Zealand administrations until they gained independence. The German colonial administration ruled Western Samoa from 1900 to 1914. From 1914 to 1961, New Zealand ruled Western Samoa under five different military administrators (Meleisea, 1987). At the outbreak of World War I in

\textsuperscript{9} The Treaty of Berlin in 1889 could not be signed due to the hurricane; ten years later, the Treaty was finally signed at the Tripartite Convention in Berlin.
1914, military forces occupied Samoa and instituted a military administration. A League of Nations mandate then placed the country under the New Zealand administration at the end of World War II. This continued after World War II, when Samoa became a United Nations trust territory, again under New Zealand supervision.

On January 1, 1962, Western Samoa, today called Samoa, became an independent state and the first UN trust territory in the Pacific\(^\text{10}\) to decolonize and become sovereign (Meleisea, 1987, p. 20; Hanlon, 1998; Salesa, 2011). The journey to this point did not come easily, and many people lost their lives organizing and struggling for self-determination and sovereignty. The Mau movement,\(^\text{11}\) the first anti-colonial movement in Samoa, was a non-violent freedom movement that dismantled the colonial rule that had been in power for almost fifty years. The Mau movement aimed to achieve self-governance and to do away with foreign involvement in Samoan affairs. The phrase, “Samoa mo Samoa” or “Samoa for Samoans” was a popular


\(^{11}\) Michael J. Fields discusses the events, which led up to the Mau movement and Samoan resistance to foreign governments and exploitation. The passing of the Samoa Amendment Act of 1947 marked the beginnings of the process whereby the New Zealand government prepared the country for transition to nationhood under the watchful ‘eye’ of the United Nation (UN). This act effectively shifted economic and political control to the Samoan people (Fairbairn-Dunlop, 1998). In the beginning of the 1920s, Samoan dissatisfaction with outsiders or external government of any kind emerged. The Mau was comprised of the Samoan community and consulting allies from overseas, who felt excluded from social life and trade opportunities. Many Samoans were against the current administration, which often dismissed Samoan customs, and dictated what the people should do or say. (See Davidson, 1967; Field, 1986; Meleisea, 1987a).
resistance slogan developed to protest New Zealand’s unilateral governance of the islands. This period in Samoan history formed the basis of Samoan-New Zealand relations today (Field, 1991). As I illustrate in the next section, Samoa’s colonial history also informed its education system and shaped its (exclusionary) educational priorities.

History of Education in Samoa

Before missionaries arrived, education in Samoan society was an integral part of the routines of daily life. Despite the missionaries’ efforts to formalize educational institutions, most Samoan education remained informal, with the purpose of introducing children to community beliefs and practices. The learning process began at birth and often involved the collective household (Keesing, 1975). I argue that historically, the educational structures in Samoa excluded people with disabilities and poor people, and the organization of schools like Aoga Fiamalamalama and Loto Taumafai was significant because they interrupted these exclusionary practices.

Mission Schools

John Williams of the London Missionary Society (LMS) arrived in Samoa in 1830 with the objective of converting the Samoan people to Christianity. He followed the “established missionary strategy of seeking the sponsorship of a powerful chief” (Coxon, 2007, p. 268). With the help of a Samoan who joined Williams’s ship in Tonga, he found his way to the village of the paramount chief, Malietoa Vainu’upo. The chief welcomed Williams and the eight missionaries who accompanied him to spread the “Word of God” around Samoa. Malietoa Vainu’upo accomplished several tasks, including becoming a Christian. He maintained rule as chief and carried on the “missionization” process throughout the 1830s (Meleisea, 1987). Just
before Malietoa Vainu’upo’s passing in 1841, he expressed his hopes for Samoa to continue to live according to the Christian values of peace and harmony. Unfortunately, peace did not last long; a series of major civil wars broke out, the last of which continued until the end of the 19th century. Many of the conflicts and struggles among the Samoans were about the land rights and chiefly titles. These challenges greatly enhanced the appeal of the Christian message of “peace” and of becoming “civilized”, thus increasing religious conversions (Mara, Foliaki, & Coxon, 1999; Meleisea, 1987a).

In terms of education, “the most significant mechanism through which the missionaries aimed to transform Samoan society into a truly Christian community was formal school” (Coxon, 2007, p. 269). The conversion process went beyond indoctrinating the “natives” to the notion of a “true” god; it also involved introducing Samoans to (white, middle-class, Christian) European values and notions of “civilization”. According to Protestant Christianity, believers needed to know how to read the Bible or the “Word of God”. The LMS quickly launched a formal school, which taught the Samoans how to read and translate the scriptures. As Baba (1986) argued:

The missionaries were concerned with total societal change and both the church and the school played a part in that effort. The islanders were not only converted… they were also introduced to new and more “civilized” ways of living, based on Christian principles. The school became an agent of change and it taught the package of skills necessary for living in what was conceived …as constituting a Christian society. (p. 83)

The Bible and other religious writings were translated into Samoan. Literacy skills were very much associated with Europeans’ ostensibly “superior” technological knowledge. Samoans who could read and write in Samoan and English were recruited as teachers at LMS, which further
helped with the church’s aims of widespread conversion. For example, one of the first educational institutions established in Samoa was the Malua Seminary, started in 1844 by the LMS with the purpose of raising the educational standards of Samoan teachers. With its combination of general and theological education, Malua trained the Samoan ministry to be both evangelists and teachers (Coxon, 2007, p. 270).

Despite Samoan resistance to leaving their villages, the Christian project still succeeded in terms of conversion and instigated a migration to central mission stations located in towns. To the credit of the missionaries, they took seriously the villagers’ concerns about leaving their village, fono (meetings), and matai (chiefly obligations); therefore, the church structures adapted to the fa’a Samoa or Samoan way of life and created Aoga Faifeau or pastor schools to meet the locals’ needs. This flexibility displayed by the church toward the Samoan people helped to smooth the way for other changes instituted by the church. As Tanielu (2000) asserts, for instance, Aoga Faifeau was to become the primary agency of formal education and training for subsequent generations of Samoan culture.

In addition, the Aoga Faifeau was a very inclusive space in terms of which students could attend the school. A friend once shared with me, for example, that in the 1970s, her teacher at the aoga (school) had a physical disability. Although her teacher had a visible physical disability, she was still respected and active in their community. She was passionate about teaching, even though she was a fa’afafine, meaning a man who identifies as women (read as third gender), and a firm disciplinarian. In essence, her presence in the community and church seemed to overshadow her physical disability and gender expression. My friend later clarified that the children respected their Sunday school teacher, or more aptly, “We were scared of her because she was strict” (Iga, field notes, January 21, 2013). From the perspective of my friend’s
memories as a young child, the ambiguity of disability, gender, and exclusion seem to fall to the wayside in this example: above all, her teacher’s contribution to the wider community was valued. Sina, a founding member of both schools, recalled that her son went to Sunday school even though he was the only one with a disability there. “He [Gele] wanted to go with his brothers and sisters and I said okay, why not.” These anecdotes illustrate some of the complexities of exclusion and inclusion in the spheres of family and religious spaces, two very significant institutions in Samoan culture. Mission schools were significant in the Samoan education system because they laid the foundation for formal schools on teaching Christian principles and training teachers.

**Samoan’s Education System, 1900-1959**

In Western Samoa, the period of German administration from 1900-1914 brought few changes to the education system. However, the shift from German rule to a New Zealand administration from 1914-1962 set the pattern of education structures that continue today (Gannicott, 1990). The mission schools emphasized religious instruction and were the most significant mechanism through which the “missionaries aimed to transform Samoan society into a truly Christian community” (Coxon, 2007, p. 269). In terms of education, “the German rulers of Western Samoa were content to leave education in the hands of the churches” (Coxon, 2007, p. 272). This continued the close and intersecting relationship between the church and state.

During the nineteenth century, racially segregated schools existed in Apia. For the duration of German rule, the schools taught the German language in the curriculum. Three government schools were established in Apia: Leififi School was established for expatriate and local European children in 1905; the Malifa School was built for Samoan children in 1908; and, a boarding school for boys, also called the Malifa Primary or Secondary School, was started in
1909 (Coxon, 2007). These newly established schools formed what is now known as the Malifa Compound—the central location of government education. In the 1900s, Samoans had an almost one hundred percent literacy rate in their own language (Western Samoa, Department of Education, 1980, p. 1). From 1920 onwards, the New Zealand administration shifted responsibility for education to the state, and secular schools started in the villages. Secular and missionary schools co-existed in many villages. During this time, formal schooling was not a right for all people. Unfortunately, only people who had the resources to pay for school tuition and expenses could attend school. The rest of the school-age population did not attend and there were no educational policies enforcing attendance. The 1950s brought about changes in the secondary education sector, such as the opening of Samoa College in 1953, Avele College (1924) and Vaipouli (1922) College, which provided secondary education (Gannocchi, 1990, p. 26).

For the Pacific region, colonization and militarization are not new phenomena. For instance, much of the wider Pacific, ranging from Polynesia to Micronesia to Melanesia, has been or currently remains under colonial rule. Specifically, island groups such Hawai`i were territorially incorporated in 1893 into the U.S. After an American military occupation and in support of a takeover of the Hawaiian government by missionary descendants who were wealthy executives (Trask, 1999). Post World War II, the island of Guam was under Japanese occupation, before coming under American occupation without a vote of consent or dissent by the indigenous people. Other islands such as Belau and the rest of Micronesia transferred from the United Nations to U.S. control. Meanwhile, American Samoa separated from Western Samoa after World War I, and up to the present day, these island archipelagoes have never reunited. As these cases demonstrate, U.S. hegemony in the Pacific, without the option of self-
determination, is also about land dispossession, economic dependency, and cultural exploitation (DeLisle, 2007, Hall & Kauanui, 1996, Teaiwa, 2005).

By 1947, New Zealand’s Prime Minister, Peter Fraser, emphasized the responsibility of the New Zealand administration as trustees for promoting indigenous political development. His administration pursued three main objectives: (a) to establish Samoan custom and tradition as one of the foundations of the future political structure; (b) to confer immediately a substantial measure of political responsibility on the Samoan leadership; and (c) to recognize and accept Samoan aspirations to complete self-governance (Powles, 1973). These three emphases also influenced educational policies, as Samoans felt that the education system was another potential sphere to make changes. For example, the Educational Act 1959, no. 14 focused on the responsibilities of the Department of Education to establish and maintain government schools. Sadly, this educational policy did not consider or address the responsibility for educating people with disabilities.

**Education System, 1960-1969**

The subpar and poor conditions of the education system in (Western) Samoa was noted by New Zealand’s Director General of Education C.E. Beeby and his delegation in 1945. This prompted both a long-term, comprehensive plan to overhaul of the entire educational system and a short-term plan to educate a small group of elite students, based on their merit and leadership abilities. Groups of Samoan students went overseas for educational training. This approach fostered meritocracy as an eligibility precursor to receiving a secondary education. At the time, Samoa did not have a secondary education system with adequate curricular standards. Educators selected only the top-performing students to go to New Zealand for secondary training. Over the next few years, “the Grade 2 schools upgraded their program to a Standard 4 (Year 6 or Grade 6)
level and four Grade 3 district schools were established to take selected students up to a Form 2 (Year 8 or Grade 8) level” (Coxon, 2007, p. 281). Subsequently, educators added grade levels and scholarship initiatives to support and prepare students to send to New Zealand for higher education training.

By 1962, Western Samoa had become an independent state; however the education system was still dominated by the “…organization, curricular, pedagogical, and assessment prescriptions of the New Zealand Department of Education” (Coxon, 2007, p. 284). An ongoing concern of Samoan leaders was to increase the pool of able-bodied and educated citizens to initiate self-government. They viewed having trained teachers and a secondary education system as essential in order for Samoa to move forward with its goal of independence from New Zealand. As a result, Samoan leaders initiated a levy of one pound for matai (chiefs) and five shillings for taulealea (untitled men) to send some of their sons to New Zealand for education (Meleisea, 1987). The manner in which students received nominations for a secondary education reveals another side of educational access, in that people with resources and gender privilege were privy to these options. Likewise, valuing student performance on standardized tests became another central indicator of their potential success in school.

Throughout the 1960s, the education system was in for more changes involving new ways to sustain new grade levels and to recruit trained teachers and staff. Most importantly, the educational goals were also changing to reflect the newly independent state. For example, groups of teachers, health care workers, and policy makers were sent abroad to further their training. By this time, nearly 80% of primary age children were attending school. Yet, New Zealand continued to provide much of the workforce in the government schools. The anticipated
goal of sending students abroad was to have these students return home and work in the
government offices.

As Samoa was preparing to become independent from New Zealand, Tina, an
administrator for the Ministry of Education in the 1970s, recalled the focus on education at the
time. She shared, “Education was the be [sic] all of everything. [We were] out to get
independence or le maua ai le mau pule and so on.” Tina related that much of the training at the
time in schools geared towards educating “somebody to teach children”. Thus, the first crop of
scholarship students trained to become teachers.

At the time, scholarships were reserved exclusively for those students who were the
“cream of the crop” or high achieving students who scored high on standardized university
entrance exams. The top ten percent of students received university scholarships to schools in
New Zealand, Fiji, or Australia. As Tina recalled, “Up to my group, we were all teachers
[especially the women]. There was no chance to say what you want--you either become a
teacher if you have your School C and UE [college entrance exams, comparable to PSAT or SAT
exams] or a stenographer or nurse.” Although, men mostly attended the previously mentioned
scholarship program, a few women like Tina also received the opportunity to study abroad.
Interestingly, the scholarships given were somewhat gendered, in that the women were
encouraged to study as nurses and teachers.

Education System, 1970-1979

Throughout the 1970s, Post-independence, the major educational push was toward
expanding school opportunities at every level. Many villages took the initiative to put their
resources and energies into developing their own schools. Although Christian missionaries had
used education as a colonizing strategy, Samoans were working within the existing colonial
education system to promote self-governance and independence. Yet, colonial infrastructures and systems of governance remained in place, and non-European people continued to live under European/Euro-American values and experienced many forms of exploitation and domination. Age-old colonial hierarchies of Europeans versus non-Europeans (Quijan, 2000; Grosfoguel, 2002) influenced those deemed educable and those considered the “cream of the crop” in terms of leadership and educational potential.

Understanding the distinction between “colonialism” and “coloniality” is relevant to how capital and occupation of lands function in post-colonial states. Coloniality refers to the continuity of colonial forms of domination that persist after the end of colonial administrations produced by colonial cultures and structures in the modern/colonial/capitalist/patriarchal world-system (Grosfoguel, 2007). Colonialism refers to colonial situations enforced by the presence of a formal colonial administration, such as the period of classical colonialism. Colonial structures and genealogies shape the intertwining narratives of schools, governance, and power dynamics in Samoa. Moreover, one cannot underestimate the entanglement of links amongst education, self-determination, and nationalist movements in Samoan history. Understanding the education system’s role in the decolonization movement is essential, particularly since education played a role in the absence of people with disabilities in schools.

By the end of the 1970s, the educational system and policies were slowly shifting again. Parents and stakeholders were demanding more support from the education system and government agencies. Likewise, the disability community and their allies were dissatisfied with slowly changing educational policies that had excluded them from schools and were now advocating for inclusion in schools. Such special interest groups were now seeking support from
international agencies to establish NGOs, as the local government did not have the resources to fund such requests.

**Education Policies**

Although parallel in structure to New Zealand’s education system, there was no mention of educating people with disabilities in the Samoan *Education Act of 1959*. The *Education Ordinance of 1959* referred to as an “Ordinance to make provisions in regard to the education of the people of Samoa” (PACLII, 2012). It was not until the act was amended in 1992 and 1993, in fact, that the language of educating people with disabilities was added to PART III of the Ordinance. The Ordinance defines terms used for discussing students in need of accommodations such as “Special class means a class in a school which is intended to provide tuition for children who for any reason require special attention or assistance in their education” (Slade, 1988, p. 23). The document also defines a special school as “a school, which specializes in the provision of education for children suffering from any physical and mental handicap” (Part I, “Introduction,” Education Ordinance, 1959, p. 23).

The addition of special class and special school sections included the role of the Chief Executive Officer or the principal of the school to collect fees from students and to redirect the fees to the educational facility responsible for the education of those students. Another paragraph of the Ordinance, set the stage for providing compulsory education for any child between the ages of five and fourteen years old or the completion of year eight (grade 8) in school. Prior to the 1959 Ordinance, not all school-age students were required to attend school. The language in the amendment included *all* students in the education system and this became a critical rallying point in the fight for the inclusion of people with disabilities in schools.
The inclusion of all children in schools also meant that the definition of “all students”
expansion to include students with disabilities, preschool age students, and poor students.
According to a conversation with Tala, a school administrator, she suspected that the Samoan
government amended the educational acts both because of community needs, but also to
participate in educational conversations at the international level (Tala, Personal field notes,
March 22, 2012). Along with the expansion in the student population, the responsibility for
educating all students would now become a government responsibility. These changes to the
policy had a profound effect on the restructuring of government schools, but not on private
schools. At the time, private schools and NGOs remained independent in terms of their
operation and admission policies.

The inception and implementation of the *Education Act of 1959* and the *Education Act of
1967* clarified the roles and responsibilities of the staff, Parliament members, and the School
Board in relation to the Ordinance. Despite clear stipulations and guidelines for the Department
of Education, there was still not a stated provision for students with disabilities in the Ordinance.
In fact, there was only one mention of “disability” in the amended *Education Act of 1967
*(section 9.3), but, ironically, it pertained to members of the Board, who could be removed for
various reasons, including “disability”.

Marshall, Mitchell, and Wirt (1989) noted that public policies reflect the cultural values
that shape institutions and traditions, through both formal and informal codes. They defined
policy as a “set of values expressed in words, issued with authority, and reinforced with power in
order to induce a shift toward these values” (p. 6). Such ideas then become educational policy,
guiding the behaviors and actions of educators and continually transforming cultural values into
policy. The disability community and their allies pushed for the amending of these educational
policies to include all constituencies. However, to understand better the educational policymaking process over time, we must understand its political-cultural evolution within a specific society (Benham & Heck, 1998, p. 18). In Samoa, the shaping of educational systems and policies occurred by colonial legacies, but also by social factors such as attitudes, genealogies of ma’i (sickness), and intra-cultural prejudices, which I discuss in the next section.

Social and Cultural Contexts: Fa’a Samoa

Within a Samoan cultural context, fa’a Samoa refers to the Samoan way of life. Samoan society and culture has had a long tradition of adopting and adapting to western influences. Fa’a Samoa is a code of ethics, values, and obligation that most Samoans are committed. As a Samoan social worker, Mulitalo-Lauta (2000) described:

The fa’asamoa is the total make-up of the Samoan culture, which comprises visible and invisible characteristics and in turn forms the basis of principles, values, and beliefs that influence and control the behavior and attitudes of Samoans. Fa’a Samoa is the ‘umbilical cord’ that attaches Samoans to their culture. It’s meaning for Samoans in their native land will be somewhat different, or have different emphases, than for those in New Zealand. (p. 15)

One example of what expectations of Samoans is the idea that individuals are never on a solo journey. Instead, individuals are a part of a collective group, whether that entails an extended family or an entire village. The basic Samoan values of reciprocity, hospitality, and respect are a “system of mutual help and kinship interdependency that is constantly reinforced by family gatherings” (Lazar, 1985, p. 162). Traditionally, the nu’u (village), the aiga (extended family), itumalo (districts), and mata’i (chief) are organized
institutions in which political structures and a council of chiefs decides the activities. This council is mostly males who hold high-ranking chief titles.

It is important to note that prior to European contact in Samoa, the islands had a decentralized system of political authority. The aiga, nu’u, itumalo, and the national government were the governing systems. Consensus is a critical component of fa’a Samoa, as it offers the means for any member of the aiga to contribute to family affairs and the political realm. Historically and presently, however, people with intellectual and physical disabilities were not involved in these governing systems. Most people with disabilities were hidden from public view or perceived as non-contributing members of the village (Lene, 2004): those considered the “normal” or non-disabled population was the community members considered eligible for leadership and cultural contribution.

Yet, Samoan oral traditions also attest to periods in which a single political authority was recognized. That is to say, a centralized Samoa existed for many centuries, as evidenced by the existing fa’alupega. A fa’alupega is a set of ceremonial greetings, recited when the fono (council) meets (Meleisea, 1987, p. 2). According to historian Meleisea, the nu’u (village) might be better understood as a “polity”. The aiga (family groups) comprise all descendants of common ancestors and make decisions on behalf of the family or village (Meleisea, 1987a). Samoans are aware of these social and hierarchal structures and the historical genealogies they embody.

Even with a governance system that strives to be democratic, contemporary literature shows a lack of awareness or sensitivity within these structures to provide adequate education and health care for people with intellectual and physical disabilities. The omission of people with disabilities from positions of power and leadership roles in the nu’u (village) symbolized
their marginal and inclusive status within village settings. This is not to say that they were never included in the family realm. People in the village also understood their role as caretakers because the perception of the disabled was that they were unable to care for themselves. Similar to the U.S. context, many people with disabilities were infantilized and made dependent on able-bodied people to provide them with daily care (Davis, 2006). In both contexts, people with disabilities occupy marginal spaces in which they are often devalued and objects of charity.

The fa’a Samoa, an indigenous institution, and a colonial educational system form the background for how the community understood members with disabilities. Both systems contributed to attitudes about hierarchy, nationalism, and productivity that lie beneath contemporary exclusive and oppressive practices. Disability Studies interrogates the construction of normalcy as a theoretical framing of disability. In other words, normalcy is a construct that also helps to construct and create the “problem” of disability (Davis, 2006; Garland-Thomson, 1997; and Shakespeare, 2006). Similarly, the fa’a Samoa institution, greatly influenced by Christian values and heteronormativity, upholds the ideology of compulsory able-bodieness (McRuer, 2006). To deviate from the norm can mean exclusion from one’s village or discursive shaming. Together, these institutions rendered people with disabilities as deviant and abnormal. One approach to resisting these normative institutions, I contend, illustrated by the case of Aoga Fiamalamalama and Loto Taumafai schools.

**Ma’i and Western Medicine**

Medical model approach to sickness and disability are inherent in dominant understandings and approaches to treatment. The medical model has heavily influenced both western medicine and indigenous notions of ma’i (sickness) and healing. For example, two sets of medical beliefs and practices co-exist in contemporary Samoa in an arrangement described by
Sutter (1967) as a “collage”. Most Samoans do not view indigenous medicine as a single, unified body of belief and practice. Many share a set of beliefs about the nature and causes of illness in general. Beliefs about the nature and causes of particular illnesses also differ significantly, in both depth and content, from one healer to the next (Macpherson & Macpherson, 1990, p. 13).

Historically, the coexistence of western and indigenous beliefs and medicine within different institutional forms has not produced significant conflict, despite their different epistemological foundations and practices. The co-existence of the two practices of medicine is due to the implementation of western medicine and health programs in Samoa. Western medical practitioners’ access to Samoan villages was limited, so the supposed superiority of Western medicine may not have had as much sway as it may have elsewhere. In order for the implementation of public health programs in the villages, the permission of the mata’i or chiefs had to be obtained. These need for Samoan cooperation “gave some control over the form of these practices and the terms on which they were offered within villages” (Macpherson & Macpherson, 1994, p. 80). In the 1970s, these two belief systems continued to co-exist, although sometimes in conflict. People nonetheless learned to navigate both systems depending on their needs.

Samoan notions of ma’hui (sickness), disability, and medical practice vary across time. In an effort to understand better perceptions of disability and ma’hui, I focus on the broader themes of ma’hui that inform Samoan views. What is consistent about these beliefs is the Samoan people’s dependence on the land to provide for their wellbeing and health. Herbal medicine and fofo (massages) are “assessment tools” illnesses or spiritual mishaps (Whistler, 1992). For instance, ma’hui aitu (spiritual sickness) and ma’hui valea (mental illness) are common “sicknesses for which
Samoans seek remedies (Lazar, 1985, p.163). The taulasea or indigenous healer also specializes in addressing illnesses caused by the aitu (spirits), and fa’ataulaitu (supernatural powers) (Lazar, 1985). As one taulasea argues:

Samoans understand their illnesses because these have been with them for as long as there have been Samoans. Europeans brought their illnesses to Samoa when they came and they brought their own ways of treating these. They understand their illnesses because they have been afflicted by them for a long time too. (Macpherson and Macpherson, 1990, p. 88)

Many Samoans accept that indigenous and “introduced” illnesses have different origins in time and space, and can therefore have different causes. In short, the taulasea (healers) attempts to “make right” whatever was making the spirits restless/angry, thereby helping the sick and bringing balance to the Samoan worlds of the living and non-living. Nevertheless, both spiritual healing and social structures reinforce the idea of a “normal” standard body and sense of well being and/or health.

In Samoa, such beliefs and practices are attributed to the many communities who have lived there. People from China, Fiji, Melanesia, Tonga, and Europe have historically resided among Samoans since the 17th century (Meleisea, 1987). Samoan taulasea or healers acknowledge that they used both Samoan and borrowed medical beliefs and practices from all of these communities (Macpherson and Macpherson, 1990). Probably the most significant contact was with the Tongans, who visited Samoa in small groups. Tongans and Samoans have a long historical relationship of forming political alliances and waging conflicts over resources.

Samoans also adopted Tongan forms of healing. As the 19th century missionary Peter Dillon (1829) explained, “Tongans were thought to be skilled surgeons and there are well-documented
accounts of quite complex surgical procedures, such as intercostal paracentesis, the setonisation of the urethra to relieve the symptoms of tetanus, and amputations” (p. 67). Religious influences and beliefs were also a part of this reciprocal and often contested relationship.

The presence of significant numbers of Melanesians in Samoa after 1870 provided yet another source from which the acquisition of medical beliefs and practices occurred. They included people from Papua New Guinea, Vanuatu, and the Solomon Islands. Many Melanesians came to Samoa by European colonial powers in the 19th century as laborers for copra and plantations. After their labor contracts ended, a number of Melanesians stayed in Samoa and some married into the Samoan community. Large numbers of Chinese laborers from Swatow in southern China came to work for the German plantations between 1902 and 1913 (Meleisea, 1987). Contact with Chinese people provided another source of medical beliefs and practices, particularly in herbal medicine. Samoan healers thus acknowledge the Chinese origins of certain “Samoan” medicines, such as medicinal concoctions from plants but as Macpherson and Macpherson (1990) argued, “it remains impossible to establish the exact nature of their contribution to Samoan paradigms” (p. 73).

In addition to understanding the various medical practices and beliefs in Samoa, the importance of social relationships cannot be overstated. In fa’a Samoa (Samoan ways of life), every individual is part of a well-defined social group or extended family. These distant relatives also include ancestral spirits (aitu), believed by many to interact with the living. The aitu cause some illnesses, such as taking on the spirit of another person or hindering the healing and health of others. However, Atua (God) is not generally believed to cause aitu (spirit) related illnesses, with the exception of the ailment called ma‘i agasala (sin). If Samoans violate God’s moral law, they may then experience adverse incidents such as death of their loved ones or unexplained
illnesses. Another cause of ma’i (illness) is the violation of tiute (one’s obligation) and reciprocity to the family. When one does not fulfill one’s obligations, disharmony can result in a death, injury, or illness in the family.

Now, whenever the taulasea determine that illnesses are of the natural world--that is, the illness appears physical in origin--they treat people with herbal medicines, changes in diet, or adjustments to their lifestyle. The taulasea also believe that the cause of some illnesses is from the positions of internal organs across the to’ala (the chest area) of a person. The belief is that the misalignment of the organs causes symptoms such as backaches and other pains, comparable to how chiropractors attribute illness to the misalignment of the spine (Whistler, 1996). Some ailments caused by the accumulation of harmful substances in the body, which are usually removed by medicines that cause the person to vomit. More broadly, the determination of whether the ailment is ma’i papalagi (European/foreign illness) or ma’i Samoa (Samoan illness) is sometimes ambiguous, but usually the distinction is clear. Sicknesses such as fulu (flu), mamapapala (tuberculosis), and misela (measles) are ma’i papalagi, while pala (stomatitis), ma’i sua (boils), and manava tiga (stomachache) were in Samoa long before the arrival of Westerners and others.

The latter illnesses are ma’i Samoa in origin, though all ailments can affect anybody in Samoa today. Therefore, the taulasea choose specific medicines based on the direction of Atua (God), even if there is no clear understanding as to how plants heal people. Generally, taulasea do not feel a need to question their healing practices, since whatever happens to the sick comes from the will of Atua (Whistler, 1996). Taulaseas also understand the value of papalagi (Western medicine) in terms of healing illnesses. Samoan taulasea often defer to Western
medicine if a person’s ailment is not improving. However, when Western medicine fails, there is seldom a reciprocal exchange with Samoan modes of healing.

This is where indigenous epistemologies of respecting all living and non-living things around us come to play. All material around us serves a purpose. By paying attention to the affective charge of matter, we also rethink the commonsense orderings of the world. This analysis of living, non-living, human, and animal pushes the limits of how social lives in our environments matter. More importantly, this perceptibility beyond humans and animals very much coincides with indigenous understandings of nature, land, and spirituality as independent and co-dependent institutions that overlap with human life. Pay particular attention to respecting the worlds of the living and the non-living that lie beyond the borders of human, animal, and spiritual matter.

Such conceptualizations of animate and inanimate matters are also relevant in Samoan values of depending on the land to provide for people’s wellbeing and health. Even with Samoan communities abroad, ma’i aitu (spiritual sickness) and ma’i valea (mental illness) are common “illnesses” for which cures are sought after by Samoan migrants, as in the Los Angeles harbor area (Lazar, 1985, p.163). Taulasea (indigenous healers) also specialize mainly in aitu (spirit-related illnesses) using spiritual medicine, supernatural powers, and fofo or massage (Lazar, 1985). The notion of “curing” depends on the illness and/or the success of the healing: later on, with missionary and colonial influences added Christian notions of healing and prayers to the practices.

Today, most Samoan healers do not consider their models less effective than those of Western medicine do; logically, neither model is better than the other is. From a taulasea’s view, each exists to understand and manage different types of illness. For healers, “the real test of the
power of models lies not in comparison of their levels of integration, or their logical structures, but in their success with illness” (Macpherson and Macpherson, 1990, p. 141). As Christian missionaries arrived, they began questioning the Taulasea healing practices, since they often equated a taulasea’s work to “witchcraft” and savage practices: today, many of these longtime, cultural healing practices are now in the category of alternative medicine. However, they still carry a stigma when compared with Western medicine (Davidson, 1967). Samoan’s understandings of the environment, people, and animals, spiritual, living, and non-living entities intertwine with co-existing categories that living people must negotiate with “those” around us. The cause of disease and illness are in relation to “something”, whether it is spiritual or supernatural, leaving the interpretations to the taulasea (healer) to remedy.

Although in general, Samoan beliefs of ma’i foster co-existence among the origins of their beliefs, the stigma of disability continues and is a contentious reminder of able-bodied mindsets and notions of health and cure. People with disabilities expose some of the limits of indigenous and western medical approaches, in that both systems seek to restore normative embodiment. The challenge with ableist medical practices is that they foster overt and covert eugenics ideologies, which seek to control and eliminate certain populations (Roberts, 1997; and Lombardo, 2008). These ideologies are, I would argue, in direct contradiction to Samoan cultural norms about the value and worth of all beings. Furthermore, the women organizers also noted this contradiction and successfully fought for educational change by underscoring the need to adhere to and follow the wider potential of Samoan principles of inclusiveness and community.
Words and Labels: Stereotypes/Tropes

Stuckey (2014) suggested that language rather than biology created what we think of as disability, especially in so-called educational or “rehabilitative” institutions. Along these lines, it is important to examine the stories of people involved in organizing the schools and to learn how they came to analyze, institutionalize, and understand notions of ma’i (sickness), disability, and health in Samoa. For this research project, participants used various terms and phrases to refer to people with disabilities. The list below shows words/terms often used to talk about people with disabilities in the Samoan context. It is important to examine language and attitudes in the stories told by the women organizers to describe people with disabilities. Regardless of the intent behind how these words and labels, the use of much of the rhetoric was in ways that were counterproductive to people with disabilities. Refer to Table A1 for more detailed description of disability language.

Stories have the power to connect us with each other. Before written language, handing down myths and legends by word of mouth existed in almost every culture. The telling of stories in carvings, etched in pictures, written on cave and tomb walls, or even sometimes kept safe in secret locations. Stories are one of the world’s oldest methods of teaching and telling history. They help us with our ideas and speak to our intellect, feelings, and spirit. Personal stories add another layer to the storytelling process. Stories show how a person tries to make sense of their world and find “their truth”. Most of all, stories offer us people’s wisdom and interpretation of past events. Cautiously, using ableist metaphors in resistance theories also show the subtle workings of power and privilege, and that is why seeking more transforming ways to how we use language can foster more productive coalitions (May & Ferri, 2005). Moreover, language used
in the participants’ stories, particularly about how core founders of the schools understood disability and ma’i are central to this project and discussed in chapter 4.

**Conclusion**

The historical backgrounds of Samoa under colonial administrations of Germany and New Zealand influenced how disability and ma’i were construed. Inherent in these governing systems were educational structures that did not educate disabled students. Exclusionary educational policies implemented in Samoa’s post-independence social structures led to the advocacy of the disability community: they and their allies helped shift these ideas. It was not until the 1990s that educational policies in Samoa considered the inclusion of people with disabilities. Such examples of exclusion continue to have profound effects on the inclusion of people with disabilities in improving their quality of life.

Samoan notions of disability and ma’i and the etymologies of such beliefs also add to the complexities of understanding one’s ability and worth. The negative language used to describe people with disabilities as “broken” or “crazy” continues to have effects on their presence in the community and schools. Even though Samoan beliefs of ma’i are reflective of physiological, spiritual, and eugenics ideas, the inconsistencies in the implementation of these beliefs in the community varies with the treatment of people with disabilities in public and familial spheres.

Lastly, the historical, social, and cultural contexts around disability in Samoa foreground the development of the schools and the advocacy work that took place to change stigmatizing beliefs about people with disabilities in schools and the community. The historical factors connecting mission schools and education reflect a colonial history of education colluding with religious conversion and missionary work. On various fronts, people with disabilities were not included in the educational structures, furthering their social and cultural exclusion. The issues
of poverty also affected the educational opportunities for some people with disabilities involved in the two schools. As this study illustrates, an exceptional case of access to education for some students with disabilities who had the financial resources and familial support. However, inherent in this access to education are also the exclusion of people with disabilities and poor communities who do not have the same opportunities to attend schools or travel overseas to seek medical services; indeed, another underrepresented facet of this research topic that needs further investigation.

Language and terms used to describe people with disabilities added to their stigmatization. However, the fa’a Samoa also had great potential for use to argue for change. These paths prompted the women organizers in this study to act and develop the first schools for students with disabilities in Samoa.
Table A1

*Description of Disability Terms*

<table>
<thead>
<tr>
<th>Samoan Term or Phrase</th>
<th>English</th>
</tr>
</thead>
<tbody>
<tr>
<td>tagata mama'i</td>
<td>sick people</td>
</tr>
<tr>
<td>ulu ka'e</td>
<td>broken head</td>
</tr>
<tr>
<td>valea</td>
<td>stupid</td>
</tr>
<tr>
<td>vale</td>
<td>crazy</td>
</tr>
<tr>
<td>tamaiti mama'i</td>
<td>sick children</td>
</tr>
<tr>
<td>mala</td>
<td>curse</td>
</tr>
<tr>
<td>leaga le mafaufau</td>
<td>bad/broken brain</td>
</tr>
<tr>
<td>leaga le ulu</td>
<td>bad/broken head</td>
</tr>
<tr>
<td>ulavale</td>
<td>mischievous</td>
</tr>
<tr>
<td>ulu ka'e</td>
<td>crazy head</td>
</tr>
</tbody>
</table>
Chapter 3

Methods

In this qualitative study, I examined the recollections, experiences, and perspectives of parents, community organizers, women with disabilities, educators, students, and government officials who founded two schools- Fiamalamalama and Loto Taumafai, for students with disabilities in Samoa. My research focused on the founding members of the schools and their experiences during the first 10 years of these schools existence. Through interviews, storytelling, participant observations, and archival documents, I explored the multiple roles (e.g. parent of children with disabilities, business owner, educator, disabled student) that these individuals played in the organizing of the schools.

This chapter discusses the methodological approach used in studying the experiences of the schools’ organizers. Next, I focused on the detailed information about the setting of the study and information about the participants. The following section examined the process of my data collection, including interviews, oral history, archival documents, and participant observations. The data analysis section highlights grounded theory and ethnographic methods as guides to my analysis process. Lastly, I examined the ethical considerations and the contributions of this study to the field.

Storytelling, Talanoa, and Qualitative Methodology

Methods refer to particular tools used for research, whereas methodology connotes the process of theorizing about the research practice. Storytelling, in this study, is an analytical framework. I used the approach of storytelling, understood conceptually as language with
vocabulary, grammar rules, norms of communicative behavior, and narrative forms, all situated within particular histories, cultures, and communities. Storytelling (as I use it here) refers to specifically a type of narration, such as the relating of narratives in person, orally (or by sign language), to an audience of at least one person (Ryan, 1995). Stories also have power; they can invite a paradigm shift to catalyze transformation. Storytelling require no special equipment or training; it is technically and intellectually accessible and potentially empowering (Senehi, 2002). Storytelling may contribute to a collective story in which indigenous people have a stake.

I employed indigenous uses of proverbs or storytelling to ground my research. The constant reminder as I conducted this research was never to forget my roots. Baldwin (1984) in Notes of a Native Son captured this lesson:

I know…that the most crucial time in my own development came when I was forced to recognize that I am a kind of a bastard of the West; when I followed the line of my past I did not find myself in Europe, but in Africa…this meant in some subtle way…I brought to Shakespeare, Bach, Rembrandt, to the stones of Paris, to the cathedral at Chartres, and to the Empire State Building, a special attitude. These are not my creations, they did not contain my history; I might search in them in vain forever for any reflection of myself. (p. 6)

An approach to contesting colonial knowledge uses stories to teach history, according to Hawaiian historian Jonathan Kamakawiwo’ole Osori. He spoke of post-contact chiefs in Hawai’i as “real people acting in very understandable ways” (2004, p. 14). Osorio argued that, for Hawaiians, ancestry is the root of everything we know and everything that is knowable about ourselves. He stated, “I teach and I write mo’olelo--not history, perhaps as you all know it, I tell stories” (p. 14). Perhaps, the most powerful element of Osorio’s writing is his self-reflexivity;
that is, he positioned himself within the histories of the people he studied. He puts faces to his ancestors by linking them with the people of his day. He also talks about reconstructing the characters of the past through spoken tales and published accounts of their exploits (Maaka, 2004). In this way, Osorio evoked the very stuff of life—things that enter, grasp, and shake our beings and become the events we remember or forget. His methodology of storytelling has relevance of all indigenous peoples; that is, he asserted how ancestry is the root of indigenous knowledge and identity (Maaka, 2004). Storytelling as Osorio’s work suggested is central to our human existence, while they also teach us about history. Likewise, I used stories in this study to help us find meanings. Thus, the idea that we tell stories because we want to understand the world and our role in it greatly informs the energy of this study.

I used the approach of storytelling as a strategy to inform anti-racist work, to teach history, and to reinstate identity and culture. Conceptually understanding storytelling as language with vocabulary, grammar rules, norms of communicative behavior, and narrative forms, all situated within particular histories, cultures, and communities. Language can be a tool to encode culture of a particular community, which includes shared understandings of identity, power, history, values and utopian visions (Senehi, 2002, p. 43). The mode of effective history, though, is political in nature. The present political options seem constrained by their histories, but these histories are open to ruptures, and tales of impossibility. The political option comes into play by choosing storytelling locales and the answers they generate.

Storytelling is a methodology that fits the needs and traditions of specific indigenous communities; anchored both in the academy and within indigenous communities. As Smith (1999) explained, “storytelling and oral histories are integral parts of indigenous research” (p. 144). She related, “Each story is powerful. However, the point about [sic] the stories is not that
they simply tell a story, or tell a story simply. These stories contribute to a collective story in which every indigenous person has a place” [sic] (p. 6). In the spirit of sharing stories, which can give others with similar stories the strength, encouragement, and support they need to tell their stories, I also paired this approach to storytelling methodology with *Talanoa* (talking). Talanoa is a Samoan concept and practice of talking through matters of importance, meaning literally to have a conversation face-to-face that is either formal or informal and involves multiple layers and levels of critical discussion (Vaioleti, 2006). Such methodology signifies culturally appropriate practices of respect, especially when talking to elders in a community. As Vaioleti (2006) argued, Talanoa is “a cultural synthesis of the information, stories, emotions, and theorizing … [that] will produce relevant knowledge and possibilities for addressing Pacific issues” (p. 21). In other words, Talanoa firmly places the power to define ideas between the researcher and the participant. Tala literally means to inform, tell, relate, command, ask, and apply. Noa means any kind, ordinary, nothing in particular purely imaginary (Vaioleti, 2006). Thus, as I collected data, I listened to how women organizers co-created knowledge and solutions for themselves. More importantly, the Talanoa approach encouraged and required that I adopt culturally appropriate procedures when conducting my fieldwork. Talanoa is not just about chatting, but also involves deep, interpersonal relationships, the kind of relationships in which most Pacific activities are carried out (Morrison, Vaioleti, & Vermeulen, 2002). Talking in-person is a highly valued characteristic among Pacific cultures, which embrace oratory and verbal negotiation and this practice has deep traditional and cultural roots. A limitation of the Talanoa method is that it is very time consuming and the researcher and the participant must develop a rapport and forge a relationship before engaging in “interview” questions. As common in most Pacific and non-Pacific communities, participants will disclose information
only when they feel and sense the time is right, when establishing trust, and when the context is appropriate.

My study on Fiamalamalama and Loto Taumafai Schools is an example of resistance to the educational policies and cultural stigma of ma’i or disability. In addition to storytelling, I used qualitative research strategies of in-depth interviewing, together with “unstructured” or “open-ended” (Bogdan and Biklen, 2007) interviewing, to gather insights about how the women organizers came to develop their perspectives. Collectively, these methodological approaches work as a means to collect data and present the data in a structure of a story.

**Research Settings**

The Aoga Fiamalamalama and Loto Taumafai schools are non-governmental organizations (NGOs) that provide medical, educational, and rehabilitation services for disabled children with a wide range of conditions ranging from physical to intellectual disabilities. Within the grounds of Aoga Fiamalamalama are classrooms, a workshop garage for activities, such as carpentry, theatre, and art. In another building is an open room with a kitchen. This space is often used when the students eat breakfast and lunch. All of the meals served at the school use healthy locally grown ingredients (Sharon, personal communication, January 30, 2013). Upstairs, above the large kitchen, are several rooms, including a one-bedroom apartment located on the east side of the building, reserved for the volunteer at the school (e.g. Peace Corp., Aus Aid or New Zealand volunteer). Another room on the west side of the building includes stalls and chairs reserved for the visiting professionals, such as audiologists or speech language specialists, who visit the campus intermittently.

Loto Taumafai is located in a different village called Moto’otua. The school occupies a one-story building with 4-6 classrooms and two offices. On the west side of the building, is a
playground with slides and swings. In the back of the building, is a long ramp, which leads from
the school building to the school bus parking space. The school is across the street from the
main hospital on island. On the mountain side of the building is a craft and arts workstation,
where most of the adult students produce artwork to sell at the local markets or businesses.
Within the patio room, is a carpentry section that makes furniture for the public.

Both schools serviced different populations of students with disabilities. Fiamalamalama
mostly enrolled students with intellectual disabilities while Loto Taumafai worked with students
with visible physical disabilities. Students with other disabilities attended either school.
Established in 1979, Fiamalamalama is mostly for students with intellectual disabilities. The
following year, the group created Loto Taumafai for students with physical disabilities, since
Fiamalamalama did not have the capacity to service these students. Thus, some of the same
founders of Fiamalamalama also co-founded Loto Taumafai School. In order to support all these
activities at the schools, much of the financial support depended heavily on donations from
international aid agencies, international private donors, local fundraising activities, and meager
fees collected from its students. Salaried administrators and teachers work at both schools, while
the board members and founding members were volunteers.

From 2011-2013, I visited both schools three times. During the first two visits, I worked
on establishing relationships and introducing my research. For the first visit in March 2011, I
spent a month on island conducting preliminary research. The second visit to Samoa on
September 2011, I was able to stay for two months and conducted further preliminary research
and networked with potential participants. The last two visits were in May and December 2012;
I visited for three months at a time and conducted interviews, archival research and school
observations. Due to the high cost of traveling to Samoa, I separated my visits into four separate
research trips within the time span of two years. I tried to travel during times in which many of the participants were on island and before the holiday season, which was from December to February. It seemed that no matter how careful and meticulous I planned my research trips, the “ideal” trip never materialized. Therefore, flexibility with my schedule and making use of the time that I spent on island were extremely important. Because I have friends and family in Samoa, it was sometimes difficult to try to accommodate competing events like family gatherings and meeting with friends. Given the comments made by many of my relatives, such as, *Se, ka e pisi kele* (or Geez, you are busy); I worked hard to balance non-research commitments with the primary purpose of my visits. My relatives often referred to my “busy” schedule of meeting people from the morning until dusk, which in the Samoan context is the marker of the day’s end. Sometimes, I would have to meet people after work, for instance, at their family business. At times a nephew, niece, or both would accompany me to meet a participant because it was “dark” and I should not be out alone. Despite the peculiarities of doing research in a Samoan context, I was very much aware of the cultural expectations that were in place and my multiple roles in each of these spaces. Specifically, I was cognizant of my gender and generational differences and their impact in terms of my relation with my participants. I had to consider the complicated and gendered rules of engagement and cultural protocols within Samoan culture and negotiate how these “rules” have also changed over time. These considerations all necessitated that I reflect on my own identity as a Samoan woman conducting research within my own community. Although, many of the participants I interviewed were openly “proud” of my status as an educated woman and of the topic of my research project, I was keenly aware of the gender inequities and power relations within these positions of power.
The physical embodiment of middle-age males in positions of power within the government offices or as heads of various governmental departments offered a visceral reminder of the status of patriarchy and hierarchy in Samoa. Moreover, gendered ideologies presented, performed, and normalized in everyday conversations, policies, and culture. Thus, my observations of gender disparities motivated me even more to carry out this research. As Lisa explained:

We don’t want to be equal with the men; the women have their roles and expectations that we are well aware of. What we want is an opportunity to also be at the table when decisions are made, which will affect us. (Personal communication, February 7, 2013,)

It is these understandings of power sharing and inclusivity that Lisa speaks of that I hope to expand further in this project.

Before conducting my research, I had to get approval (IRB #12-277) from the Board members of both schools. Upon receiving the green light from these organizations and the Syracuse University IRB office, I first contacted the founding members who were still on island. The administrators of both schools asked me several times if I wanted a job working there. I kindly replied “no”, but offered to do more with the schools once my research project was completed. I explained to both administrators that this would be a conflict of interest and that I wanted to focus on my role as a researcher for now. Most staff members understood my concerns and agreed to continue to work with me.

Although gaining access to do research with Fiamalamalama and Loto Taumafai schools was relatively relaxed, it took time to get institutional approval and to contact potential participants. I attribute this to my Aunt Sina, a founding member of both organizations. Before
physically going to the schools, I wrote to the current administrators Leta’a (Loto Taumafai) and Sharon (Fiamalamalama) regarding my project. They both put forth my request to do research to the Board of each school for approval.

My research focused on the period 1970-1980, a critical post-colonial period in which the education system in Samoa was transitioning. This transition time was chaotic due to changing of governance and power relations within the entire country, but it was also a prime time for the disability community to advocate and assert their needs. The school founders of Fiamalamalama and Loto Taumafai collaborated with the Early Childhood educators to elicit government resources to create the schools. While the current events in these two schools were not the focus of my study, these events still informed my research. Particularly, I was most interested in the founding years of the school and the experiences of its members and students in navigating the competing discourses of disability that were circulating at the time. Therefore, I went to the schools only to interview specific staff members who met the criteria of my research project and to meet with the administrators. The criteria for selecting the participants included:

1. Any founding member or community member (defined as people who lived in the community who were not educators, government officials, or parents of disabled students) affiliated with Fiamalamalama and Loto Taumafai schools during the 1970s-1980s;

2. Former students, educators, or staff members who were at these schools during the 1970s-1980s; and,

3. Any government officials who were in education-related positions during the 1970s-1980s, which was the focus of my research.
Although I tried to locate students who fit the second criteria above, I was only able to connect with two former students whose dates of attendance did not line up with the first years of the schools. Including their stories was important however to elicit a student perspective, which I focus on in Chapter 6.

I conducted the majority of my research in the participants’ home, cafe, or other locations of choice. My field notes documented the answers to the following questions:

(1) How did you become involved with the school(s)?
(2) What was your role in the school(s)?
(3) What was happening in Samoan education during 1970-1980?
(4) How do you define disability or ma’i?

Thus, I was able to frame my research questions to both elicit their stories about the schools, but also to focus on how the founding members constructed and understood the meanings of disability through their everyday experiences. My initial questions to the organizers who were also parents focused on their motivation and interest in starting a school for disabled children. In terms of the educators, administrators, government officials, I was particularly interested in asking questions about the institutional history of the schools and the policies, and attitudes of top-level officials, which informed the education of all students. For participants who were community members, I geared my questions on how they understood disability and why they got involved in the schools. It was difficult to locate all of the core founders of the schools because most of them have moved off island or passed away. When speaking to the two former students of the schools, I was especially interested in their experiences at the schools, how they felt about going to the school(s), and how critical were these schools to their lives. There were some difficulties in this area too, as most of the founding students of the schools
have also passed away. Fortunately, however, I was able to interview two former students, one from each school.

**Data Collection**

The data collected for this study came from multiple sources and at multiple times in the span of two years. The primary sources were in-depth interviews with parents and community members involved with the founding and operation of Aoga Fiamalamalama and Loto Taumafai. The collection of the secondary data was from documents from public and university archives (e.g. newsletters, government documents, correspondence, newspapers), and participant observations at school meetings and events.

**Participant Selection for Interviews**

I interviewed four groups: (a) women organizers and parents; (b) former staff; (c) former students; (d) community members (those involved in the schools, as indicated by their peers and school documents) and (e) government officials. I conducted 18 semi-structured interviews, as a way to gain insight into the creation and social context of these schools (Wengraf, 2001). The interviews were informal and allowed for some flexibility in the process of interviewing. Through these interviews, I learned what people perceived and how they interpreted their actions. Another benefit of using semi-structured interviews was the opportunity to gather comparable data across participants. Because participants had different perspectives and experiences, the semi-structured interviews allowed for tailoring each interview to both shared and idiosyncratic elements of their experiences (Bogdan and Biklen, 2003). Since the majority of participants interviewed ranged from parents to students and from educators to village elders,
I used different semi-structured interview formats and questions per group and person (see Appendix A).

The participants were selected through a purposeful sampling technique (Bogdan et al., 2003). They were not randomly chosen, but selected based on their knowledge of and their previous affiliation and role with the two schools from 1970 to 1980. As stated, this period is crucial because of the educational reforms that were happening at the Ministry of Education, including adding secondary grade levels, preschool classrooms, and vocational training courses. More importantly, a reorganization of the nation’s education system, since gaining independence from New Zealand rule in 1962, highlighted a transformative time in which governance was shifting from foreign or colonial rule to the local indigenous government (Meleisea, 1987). During this time, however, much of the reforms happening in the education system did not include students with disabilities. The creation of the two schools that are the focus of this study demonstrates the disability community’s contribution in reshaping dominant structures, such as education, to be more inclusive of all students and to rethink dominant notions of disability, citizenship, and educability.

With an understanding of language as a non-neutral medium, I conducted interviews in order to help gain a greater insight into the understandings and development of critical consciousness and how this informed the creation of these schools (Guajardo, Guajardo, and Casaperalta, 2008). Specifically, my questions attended to participants’ meanings of disability as well as how those various perceptions shaped their involvement with the school(s).

To initiate the selection of people to interview, I set up individual meetings with the current principals of the two schools. From these two separate meetings with Sharon (Fiamalamalama) and Leta’a (Loto Taumafai), I received the names of core founders of the
schools, as well as their names, addresses, and telephone numbers of those they believed I would be able to interview. They both discussed founders who were now deceased and founding members who were no longer with the schools for health or other reasons. I was able to obtain some names from my aunt who was one of the founding members of both schools.

Upon receiving the names of potential participants, I emailed most of the participants ahead of time before I arrived on island. In my email, I attached a copy of the description of my study. At the bottom of the page, I also attached another page, which was a request for interview volunteers if they themselves have played a founding role in the schools development, as a parent, community member, or educator. I also included the dates that I would be physically on island to conduct my research. People could also recommend others for interviewing (Baba, Mahina, Williams, Nabobo-Baba, 2004). Most participants responded to my requests when I met them face-to-face, but this initial email was important to make at least an initial contact. This research project was verbally “advertised” by individuals in the Special Education units at the National University of Samoa and the Ministry of Education to their colleagues and by the Board members of Aoga Fiamalamalama and Loto Taumafai. Family members in Samoa were instrumental in locating the whereabouts of some of the participants and helped to me to connect with them.

When I arrived on island, I contacted all the individuals that emailed and made appointments to meet in person. Unfortunately, on my last research trip on December 12, 2012, Cyclone Evan, a category 3 typhoon destroyed many of the homes and buildings on island. Many people did not have running water, electricity, and some lost their homes and businesses due to the high winds and flooding waters. Luckily, there were no fatalities, but major structural damage to many houses and businesses. Needless to say, agreeing to or scheduling an interview
for a research project was the “last task” on my participants’ to-do list as they scrambled to rebuild their homes, businesses, and recover from the storm. During this time, I too provided cleaning services and helping family and friends salvage what was left of their belongings. At the same time, the aftermath of the typhoon also affected me physically. Due to the intense heat and humidity, both of my arms were covered with heat rashes and they eventually swelled up. Despite the use of heat rash creams and allergy pills I took with me, the heat rash seemed to get worse each day. Finally, after a week and a half of not being able to move my arms, I decided to go to the local taulasea (healer), for help. Lafo, the local taulasea in my village of Vailoa lived down the street. She gladly massaged me as she had when I was an infant. As an infant, I had something growing around my neck called seasea (heat rash). Despite the fact that she was now 83 years old, Lafo fondly remembered my siblings and me as young children at church. She even recounted all our names and ages.

After the fofo (message) of my arms with lega (sulfur powder and coconut oil), she instructed me to leave the greasy concoction on my skin for 24 hours. She also instructed me to not shower for a day, which was hard to do given the heat. Taking a cold shower in the islands was my saving grace from the piercing hot heat and suffocating humidity. Nevertheless, I listened to Lafo’s instructions and slept that night without washing my dirty feet and sweaty body. It was not a great feeling. On the second day after the fofo (massage), the swelling subsided and I could slowly bend my arms. Three days later, my arms returned to their usual size and I could freely move them. Lafo instructed that I use the nonu plant’s leaves to cool down my body daily. She attributes the heat rashes to the “suiga o le tau” (change of weather). Of course, a research project was also the last thing on my mind as I was trying to adjust to the humidity and heat.
Because of these events, it took me about four weeks before I could begin interviewing participants. Another difficulty was that many of the participants were traveling by this time. December and January are the “holiday” months for people in Samoa so many of the government offices and schools close for six weeks. Many people were also off-island visiting family and friends in New Zealand, Australia, or the US.

During my initial in-person contacts and interviews, I asked participants for recommendations of other people who may have been involved in the founding years of the schools or any individuals who had remained involved throughout. I kept a running log of people mentioned who were instrumental at one time or another during the 1970-1980s for future contact. I also interviewed two women educators, Tina and Pua. The women were leaders in the education system; however were not founders of the schools in this project. Tina and Pua worked at the Ministry of Education and the Seminary Colleges during the time I was studying. They were both teachers and administrators in these settings for over 20 years. Their input greatly added to the conversation about education of all students in Samoa. Tasi was another former school administrator in the Ministry of Education that I interviewed about her views on educational policies and the education of students with disabilities.

In order to establish rapport, it was important to verify for each of them that the schools endorsed my project. I first established contact with these individuals in 2011 and continually fostered my relationship with them. Even more importantly, participants wanted me to share my own genealogy and establish my family kinship with participants they knew. The important units of Samoan social organization are the household (fua’ifale), the extended family (aiga), and the village (nu’u). Samoans also claim membership in a given aiga (family) by virtue of blood,
marriage, or adoption, which means all Samoan aiga are large (Holmes & Holmes, 1992; Meleisea, 1987).

A necessary verification of my relationship to Sina and my extended family ensured my access to the participants in my study. This process was an example of the multilayered, shifting, and competing similarities and differences between native or insider researchers who are researching their own communities—a process that is shaped by simultaneous, ongoing negotiations (Vó, 2000). Burawoy (1998) regards ethnography as a distinctive form of social science inquiry that bridges two competing models of science—positive and reflexive. He describes positive science as research that “works on the principle of the separation between scientists and the subjects they examine”; whereas reflexive science “takes as its premise the intersubjectivity of scientist and subject of study” (p. 4). Based on these two models illustrated by the emic stance of Vó and the reflexive stance of Burawoy, I maneuvered the shifting and overlapping nature of my own subject position in relation to my participants and the study.

Interestingly, no one asked if any of the founding members endorsed the project. In fact, most of the founding members affiliated with the school were pleased with my project and were very honored that I was doing research on them and their schools. They also gave me their blessings in completing this project and sharing it with the community. Because, in part, this study is a vehicle for recording history and the telling of an unknown story in Samoa, everyone I encountered generally supported the research study.

I audiotaped each interview, each of which lasted from 1-2 hours. Using pseudonyms protected the anonymity of all the participants in the study, except for those participants who requested that I use their first names. Eight individuals in the study did not want their interviews audiotaped; therefore, I only took notes during those meetings. I had to clarify for each of the
participants that I was writing an historical account of Fiamalamalama and Loto Taumafai and believed that it would be fuller and more accurate if their role in its development and perspectives were included. At the beginning of each interview, I reiterated my goals and motives, since most participants asked again for me to describe what I would be doing and why I was doing this project. Following this clarification and confirming my family genealogy for them, people were open, friendly, and candidly shared their stories.

Some participants, wanted to know who else I had spoken to before their interview and, in some cases, asked if I had also spoken to “x, y, or z”. If the person was an elder, I would respectfully defer to their suggestion and write the name down that they suggested, as a sign of fa’aaloalo (respect), even though I might have already spoken to the person they were suggesting. After the first few interviews, I learned that most had already spoken to someone else I had interviewed. Hence, after a few interviews and word got around, I found little to no resistance to scheduling times for participants to meet with me.

All of the interviewees chose the location of our meetings. Some chose a local coffee shop or restaurant in town, some chose their homes, and some requested to meet in their work office. For every interview, I brought with me pastries or a cake as a token of my appreciation for the interviewee’s time. This was a much-appreciated gesture. What was particularly interesting about this group of interviewees was that for most of them this was the first time they talked about their work with the disability community or the schools. Hence, they did not regard their involvement as anything “special” or “important”. As Lisa explained, “You did what had to be done!”

As a group, they were eager to share their accounts of the early years of the schools they created; and talk about what they viewed as its major accomplishments. None of the
interviewees told her/his own story in terms of an individual accomplishment. The participants interviewed in this study, for the most part, showed great pride in the triumphs of the other parents and community members involved in the schools and the successes that the schools had made over the years. Some of the participants were skeptical of why I was including them in the study because they did not view their role as “extraordinary”. Instead, they viewed their involvement as simply a part of their tautua (service), or alofa (love).

It was also useful that I had worked as a special educator for eight years, which afforded me a degree of credibility beyond simply being an academic. This, combined with the fact that most people knew my family on island, gave me additional credibility as someone who, by association, was trustworthy. In addition, most of the interviewees also knew my mother and when they found out that, she accompanied me on this research trip, making me promise that she would accompany me the next time. I was sometimes frustrated that in many of these follow up sessions, the topics participants wanted to discuss did not always directly relate to my research topic; although I was always engrossed and entertained by the conversations. However, it was also true of these group meetings that participants were more open to discuss the questions I posed, given my mother’s presence. This approach for the most part resulted in an informative and sincere conversation about the schools, albeit sometimes embedded within conversations about politics and family dramas. In the end, my mother came along for two interview sessions. She enjoyed the interview process and I decided that she would have actually made quite a good principal investigator.

**Interviews**

I had initial contacts with 30 participants: Four participants declined to participate in the study; 18 participants allowed audiotaping during the in-depth interviews; and eight participants
elected not to allow audiotaping during our sessions. Of these participants, seven audiotaped interviews were with founding members of Aoga Fiamalamalama and Loto Taumafai. Other founding members who were thought to be still alive were said to have moved off island (to New Zealand or Australia, for example) and no one I spoke with had much information about where they might be or even if they were still alive. Two participants also declined my request for interviewing for unknown reasons and two participants declined due to health reasons. Thus, other than the four individuals who declined to be interviewed (founding members), I was able to interview all of the founding members who were still alive and whose health at the time did not preclude my interviewing them.

For the purpose of this study, a “founding member” was anyone who was involved in the founding years of the schools from 1970 to 1980. Therefore, people did not have to be at the first meetings or to have signed the original Constitutions of the school. I also conducted interviews with a couple whose child was in the school system at this time. Their child attended both schools in the study and is now an adult working for one of the schools. These parents ended up organizing their own NGO with other parents (going beyond the organizing of the first generation of organizers in this study), which focused on the mainstreaming of students into government and private schools. Later, this parent also became a board member of one of the schools.

I conducted both semi-structured and open-ended interviews, designed to generate free and unstructured responses (see Appendix A). A copy of the Samoan translation and accessible formats (electronic and large font copies) of the interview questions was also prepared, in case a participant requested or needed a copy. The interviews were conducted in Samoan and English, depending on participant preference. The researcher transcribed those audiotaped interviews.
For the participants’ interviews that were not audiotaped, a copy of my field notes was shared with them a few days after the interview and they had the chance to edit and revise my notes. The credibility of the translations and accuracy of information mentioned by participants were triangulated with multiple sources of data, including, participant feedback, government documents, newspapers, additional interviews, newsletters, and conversations with relatives (Denzin and Lincoln, 1994).

Conducting follow-up interviews was one of the most important ways I was able to clarify the accuracy of facts and information shared in the previous interviews. Another strategy I used was that I sent the transcribed interview transcripts to the participants and invited them to read them over and make any edits or revisions that they wanted to. This approach provided me with the opportunity to get clarification regarding specific parts of our conversation and to clarify any aspects of the transcript that were unclear. Mostly, it fostered a transparent relationship between the participants and myself; earning the participants’ trust was a factor that I valued the most during this process. The participants were grateful for this approach and appreciated the ability to re-check their comments and stories.

The following chart (Table 3.2) includes the detailed information about the interview participants. This includes each participant’s pseudonym, a vague job title, and the school with which they affiliated. As stated, the use of pseudonyms and the removal from the transcripts of any identifiable information referring to particular participants or the specific institution(s) they served ensured confidentiality. Email kept the participants abreast of the project’s progress. They were also invited to provide critical feedback on its “accuracy, completeness, fairness, and perceived validity” (Patton and Patton, 2002, p. 560).
### Table 3.2

*Participant Information and Relation to the Schools*

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Role in the schools</th>
<th>School(s) of affiliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sina</td>
<td>Parent; community organizer</td>
<td>Fiamalamalama &amp; Loto Taumafai</td>
</tr>
<tr>
<td>2. Leta’a</td>
<td>Administrator</td>
<td>Loto Taumafai</td>
</tr>
<tr>
<td>3. Afamasa Telesia</td>
<td>Administrator and educator</td>
<td>Early Childhood &amp; Aoga Fiamalamalama</td>
</tr>
<tr>
<td>4. Lani</td>
<td>Parent; community organizer</td>
<td>Aoga Fiamalamalama &amp; Loto Taumafai</td>
</tr>
<tr>
<td>5. Lupe</td>
<td>Educator and community member</td>
<td>Aoga Fiamalamalama &amp; Loto Taumafai</td>
</tr>
<tr>
<td>6. Sisi</td>
<td>Community member</td>
<td>Aoga Fiamalamalama</td>
</tr>
<tr>
<td>7. Sharon</td>
<td>Administrator</td>
<td>Aoga Fiamalamalama</td>
</tr>
<tr>
<td>8. Sasha</td>
<td>Former student &amp; disability advocate</td>
<td>Aoga Fiamalamalama and Loto Taumafai</td>
</tr>
<tr>
<td>9. Lisa</td>
<td>Former member &amp; disability advocate</td>
<td>Loto Taumafai &amp; NOLA</td>
</tr>
<tr>
<td>10. Foa</td>
<td>Disability Advocate</td>
<td>NOLA</td>
</tr>
<tr>
<td>11. Tasi</td>
<td>Government official</td>
<td>School Administrator</td>
</tr>
<tr>
<td>12. Tina</td>
<td>Educator</td>
<td>School Administrator</td>
</tr>
<tr>
<td></td>
<td>Name</td>
<td>Occupation</td>
</tr>
<tr>
<td>---</td>
<td>-----------------------</td>
<td>-------------------------------------</td>
</tr>
<tr>
<td>13</td>
<td>Tui Tupua Atua</td>
<td>Head of State</td>
</tr>
<tr>
<td>14</td>
<td>Dr. Viopapa</td>
<td>Physician &amp; Advocate</td>
</tr>
<tr>
<td>15</td>
<td>Fili</td>
<td>Business owner &amp; community member</td>
</tr>
<tr>
<td>16</td>
<td>Sua</td>
<td>Educator</td>
</tr>
<tr>
<td>17</td>
<td>Rosa</td>
<td>Parent</td>
</tr>
<tr>
<td>18</td>
<td>Pua</td>
<td>Educator</td>
</tr>
</tbody>
</table>
Documents

The second primary data collection source was from archives and university libraries. Documents obtained from the Nelson’s Public Library in Apia, the National University of Samoa (NUS) library, the Intellectually Handicap (IHC) archives in Auckland New Zealand, the Pacific Collections at the Hamilton Library at University of Hawai’i at Manoa (UH), and the Pacific Collections at the Australia National University (ANU). The list below represents the documents I examined from these institutions.

(1) Newsletters of the Intellectually Handicapped Inc. from Auckland, New Zealand from the 1960s to 1984. The newsletters, called IHC Newsletter, published monthly by the agency. These were rich source of information about the people, events, and news related to the organization. These newsletters also chronicle the involvements of various parents over time, their viewpoints and analyses of events, upcoming plans, strategies, and the progress within the association. Mostly, these newsletters recorded much of what was happening in the other Pacific nations and the directions taken by other organizations in those contexts. I specifically focused on newsletter items that highlighted the founders involvement in the organizations, as well as the events that IHC considered “breakthroughs” or that signaled a change in their perspectives, attitudes, or priorities. In addition, I also focused on the parts of the newsletters that illustrated the ways they represented parents or thought about parents and students. These relevant sections were included in my data analysis, provided an additional source of information in addition to face-to-face interviews, and allowed me to triangulate findings.
(2) Newsletters from each school. Aoga Fiamalamalama published the *Fiamalamalama News* monthly. Loto Taumafai also published a monthly report of what was happening within the school. I analyzed each of these newsletters, as available, to gain an understanding of events those parents and the schools considered important or that were “historical landmarks”. These documents were archived at the IHC New Zealand Incorporated, Willbank House, in Wellington, New Zealand.

(3) Government documents collected from the Pacific Collections located at the Australia National University (ANU) library. Documents in the J.W. Davidson Collection on the organizing of the Samoan Constitution and Samoa’s road to independence provided important context for the study. The Norma MacArthur Collection also contained documents on health policies in the 1970s and 1980s and school and health papers on dispensing services for school age children. The “Samoan Historical References” also contained papers on Samoa’s independence in 1962 and village jurisdictions of governance. Finally, the Legislative Assembly of Western Samoa was an important source for the Annual Report of the Ministry of Education from 1961-1990. The ANU Pacific Collections held one of the largest collections of documents, research papers, and personal scholar’s libraries regarding the Pacific Islands and was invaluable to this project.

(4) Government health and educational reports from the National University of Samoa’s library and the Nelson’s Public Library in Apia Samoa. Researchers from overseas compiled these health and educational reports during the 1960s to the 1980s. These documents provided a window into how institutions, such as hospitals and schools, operated at the time and the challenges they faced. These documents provided a great
resource for helping me to understand the discourse and attitudes at the time through the manner in which these documents discussed sick people, mental illness, and services. The “Legislative Assembly of Western Samoa Education, Annual Report of the Ministry of Education” from 1971-1978 was located at the Pacific Collections at UH and proved to be informative.

(5) Materials developed or used by parents themselves during the early years of the organization were located at the schools or the personal collections of the school founders and teachers. Parents and the community often educated themselves about disability by using these collections of books, magazines, pamphlets, newspaper articles, and informative materials. These materials were selectively reviewed because they were a reflection of parents and professional beliefs about people with disabilities and about the potential roles of parents at different points in time.

(6) Letters of correspondences between IHC New Zealand and IHC Samoa during the 1970-1980s. These documents became available after sending an email to the librarian at the IHC New Zealand Archive Library located in Auckland, New Zealand. The IHC in New Zealand sent me copies of papers related to the establishment of the IHC in Samoa. Much of these memos, personal letters, and newsletters revealed the inter-office workings of the organizations, as well as the challenges they tried to overcome, such as funding dilemmas for the operational aspects of each school.

Taken together, the archival data provided a window into some of the most pressing concerns and challenges of parents and the organizations over the course of the founding of the schools. The rationale for various actions and directions taken by the parents and community members on behalf of the schools was also revealing in showing how each stakeholder
understood their role. Therefore, the archives not only furnished the chronological development of the schools and broader legislative and policy context of the time, but various documents also served to capture the attitudes and beliefs that shaped those developments. The annual reports per government department also revealed the fiscal situations and challenges that schools faced throughout the years of the study.

**Participant Observation**

Starting from 2012, I gathered data through participant observation at school meetings. At these meetings, the discussion included information currently important to the schools’ functions. Also at these meetings, the airing of issues and philosophical debates occurred, which reflected contemporary beliefs and attitudes of the various “factions” within the organizations. Although these meetings were not open to the public, I read some of the meeting minutes. For both schools, I attended two meetings. For the remaining meetings, the administrators provided verbal minutes on several meetings that were relevant to the study. I also observed in classrooms at several government schools that were mainstreaming students (mostly Deaf students). For Fiamalamalama and Loto Taumafai, I also observed the daily teaching that went on at the schools. Even though these observations did not directly relate to my study, I was interested in a comparison of what had changed within these educational and learning environments from the stories that the participants shared with me.

**Data Analysis**

Data analysis is both a conceptual and cognitive process. In a qualitative study, data analysis begins well before the data collection is complete (LeCompte and Schensul, 1999, p.149; and Bogdan & Biklen, 2007). In order to discern patterns in my data and determine what
stories the data was telling, I sifted through the piles of interviews, stories, newspaper articles, government documents, healthcare documents, newsletters in order to begin to make sense of them. My in-depth interviews were my primary data; therefore, I was careful in tagging and reviewing the story themes encompassed in these conversations. The broad categories of preschool, government schools, funding, policy, culture, women groups, and health care were the initial organizing themes or threads in my analysis. I used Nvivo (software designed to analyze data) to help me sort through and establish the initial analytic categories from the data. Unfortunately, my introductory membership to Nvivo expired after several months, so I coded my remaining data manually in a process that involved re-reading through the data and highlighting the patterns that each story and document told. These patterns were then organized on a bulletin board and I began arranging and rearranging them chronologically and according to the emerging themes that were embedded in the stories that the women organizers and participants conveyed.

After this initial coding of the data, I went back through the data and color-coded six particular themes. These included:

1) The need to create schools for disabled students;
2) The women organizers who carried out the creation of the schools;
3) Stories of belonging and exclusion;
4) Educational structures that reinforced the exclusion of disabled students in schools;
5) International aid as development and funding sources for the schools; and
6) The use of negative attitudes and language toward people with disabilities.

As I continued to analyze my data, I realized that the chapters of my dissertation were slowly emerging from the analysis. The system of color-coding helped me to organize my data and sort
through the archival documents and interview transcripts. This color-coding approach also enabled me to arrange visually my data in a way that it was easy to retrieve, while writing up each of the chapters and sorting through the sub-themes in each of the chapters. I also photocopied all the documents and sections of my interviews used in each chapter. This strategy helped me to keep my materials organized and it meant that I did not have to keep moving documents around because particular portions of some of the documents were used in different chapters.

As a part of my process of analysis, I also shared portions of my analysis with several participants who were interested in providing feedback. Information such as dates, places, events, and names of individuals were crosschecked with the participant’s interviews and archival documents. I gave Sina, one of the original founders, several versions of my initial findings for her feedback. I chose this practice of sharing earlier drafts of my work with the participants to provide another member check, and to share my position as a researcher and knower (Biklen and Cassella, 2007).

**Grounded Theory**

After the initial sorting of the data, my more formalized procedure for data analysis was informed by the grounded theory approach of Glaser and Strauss (1967). Grounded Theory is a research tool that enables a researcher to seek out and conceptualize the underlying social patterns and structures of your area of interest through comparison and substantive questions that eventually turn into theoretical questions. For example, to change a substantive question to a formal research question, “change the wording by omitting phrases or adjectives” (Glaser and Strauss, 1967, p. 80). As one of my research questions show, “How did the Samoan community
understand disability?” becomes “How did the disability community and its allies approach disability as a critical lens to strategically navigate educational policies?”

As stated, the data analysis occurred in order to identify common elements, which were then grouped together into my initial categories or codes. I constantly compared these codes with each other to identify additional patterns and themes so that I could generate an interpretative framework from which to understand and explain the data. After analyzing the transcripts of the 18 interviews, I sorted through the data and generated more than 38 codes. On further refining these codes, I realized that the data could then be reorganized around three major themes:

1) How the everyday experiences of the founding members paralleled the organizing of the schools;
2) How disability was constructed through the organizational structures in education and cultural beliefs; and
3) What roles international agencies and donors played in the development and sustainability of NGOs on island.

Ethnographic Methods

An ethnographic approach to learning about the social and cultural life of communities, institutions, and other settings is likewise relevant to the cultural underpinnings of this study. The idea that we must first discover what people actually do and their reasons for doing it, before we can assign to their actions any interpretations drawn from our own personal experience or from our professional or academic disciplines resonated with my research procedures. The characteristics of ethnographic research that applied to my study include:
1) The research occurred in a natural setting and it involved intimate face-to-face interaction with participants;

2) The research sought to represent an accurate reflection of the participants’ perspectives and behaviors; and

3) The research framed all human behaviors and beliefs within a sociopolitical and historical context (LeCompte and Schensul, 1999).

Ethnography in the late twentieth century “remakes” the observer and the observed (Marcus, 1992, p. 309) in ways that create new directions and new points of departure for discussing, understanding, and finding possible solutions to social issues. In many instances, the researcher may themselves be “native” or members of the community in which they are conducting research. This situation both complicates relationships in the field and transforms the ethnographic enterprise. I think about ethnography in relation to Geertz (1973), who claimed that ethnography is not just as a means of recording different ways of life, but also as a form of writing. Geertz characterized ethnography as a form of “thick description” (p. 16). By layering meaning into closely observed details, thick description helps make people’s behavior more comprehensible even when we are not immediately familiar with their assumptions (Narayan, 2012, p. 8). I drew on ethnography first in relation to strategies of storytelling, but it also helped me to think about how stories carry personal and cultural meanings and how their telling also has social consequences.

Ethnographers are no longer the distant omniscient strangers that they have traditionally been. Ethnographic researchers have a new role in viewing and representing communities and peoples. Likewise, participants of ethnographies are not “ignorant natives” who passively accept intrusion but are continuously asking “Why?” and “What for?” The roles of participants are then
apprehended as producers of knowledge as well as products of history, and shapers and builders of culture (Manalansan, 2000).

**Ethical Considerations**

There were no photographs, video, or audio recordings of students and learning spaces collected within the school campuses to safeguard the privacy of students, families, and staff. My participants gave consent to audio record our interviews and stories (see Appendix B). For future consideration, any audio products created from the data will be made available to my participants and will be used strictly for educational purposes.

**Conclusion**

The use of ethnography and stories to share histories and knowledge was essential in the methodology for this project. My process centered on gathering and producing knowledge that allow for sharing with all parties in the community and beyond. Specifically, I wanted this research to be able to document the experiences of the disability advocates and former students of the schools during the 1970-1980, a time of great change in the education system in Samoa. I also wanted to explore how the disability community and its allies assume disability as a critical lens to navigate strategically educational policies.

An ongoing challenge in conducting this research required that I continually make sense of my role as a critical ethnographer and participant observer (Patton, 2002). Although this study took place in my own community, I did not rely solely on self-reflection as the means to neutralize bias. I claimed neither absolute subjectivity, nor absolute objectivity. As scholar Paulo Freire (1970) argued, “One cannot conceive of objectivity without subjectivity. Neither can exist without the other, nor can they be dichotomized… Neither objectivism nor
subjectivism, nor yet psychologism is propounded here, but rather subjectivity and objectivity are in constant dialectical relationship” (p. 50). This is the line I tried to maintain as I collected and analyzed my data.

In the next chapter, I focused on the funding and organization contexts of the schools. A larger history of education in Samoa, will provide a window into the context in which the organizers working to create these educational spaces for students with disabilities in Samoa. As Narayan (2012) writes, “stories often grow in groves, with some stunted by the shadows of others. Like enormous trees disappearing into the sky, big and emotionally compelling stories tend to point beyond what we can immediately see” (p. 14). To highlight some of the taller trees in this forest, later chapters will focus on the stories of how the community (conceived broadly to include participants, parents, members, students, and allies) participated in organizing the schools during the tough days of post-independence governance. The enormous branches that formed the collective history remind us that a network of relationships connects people and such connections bring about the collective harmony and well being of all.
Chapter 4

The Search for Funding and Land: The Case of Aoga Fiamalamalama and Loto Taumafai Schools

In this chapter, I recounted the story of two non-governmental organizations (NGOs), Fiamalamalama, and Loto Taumafai, started by community members in the 1970s. These schools paved the way for more services and programs for preschoolers and people with disabilities in Samoa. In addition to their grassroots origins, they also attracted financial assistance from international organizations. Thus at the core of this chapter, questions about charity, sustainability, inclusion of people with disabilities in society, and the changes within an education system. Specifically, I focused on the interdependent relationships among overseas organizations, NGOs, and the disability community.

I focused particularly on the background and context of NGOs and their role in funding the schools. Next, I discussed the role of allies like the preschool advocates and overseas aid in establishing the schools. Then, I summarized the challenges of finding land to establish the schools while also fundraising for the school budgets and staff salaries. Discussing land is essential because Aoga Fiamalamalama ended up purchasing land for the school’s home, while Loto Taumafai leased land from the local government. Indigenous understandings of land and property differ vastly from colonial claims of land as property and ownership. Generally, creation narratives, indigenous stories, and oral histories about people as the caretakers of the land are crucial components about Native society’s survival despite more than 500 years of
conquest. Furthermore, questions of land and aid weave together and there is a need to understand it in the context of beliefs of fa’a Samoa, Christianity, and modernity. In this chapter, I therefore discussed how the women advocates for the schools acquired land and monies.

I concluded by examining the implications of international aid and the future of postcolonial nations in the Pacific and beyond. Development in economy and social services sectors has relied exclusively on one knowledge system, namely, the Western one, as a way to circulate modernity among global South countries. Development has played a part in the marginalization and disqualification of non-Western knowledge systems (Escobar, 1995, p. 13). Furthermore, such NGOs are often not effective because their top-down approach disconnects from the community. Thus, the idea of channeling funds through NGOs as a solution to the problem of increasing aid effectiveness is debatable.

**Non-Governmental Organizations (NGO)**

Non-Governmental Organizations are donor-driven and often funded by private donations, as opposed to public or governmental funds. In assessing the impact of NGOs in enhancing the effectiveness of aid, it is necessary to clarify the distinction between two types of organizations based on the type of activity that they undertake. The first groups of NGOs are those involved directly in developmental activities, including the establishment of services for the poor. The second group of NGOs, geared primarily to the organization of civil society and of services that local governments do not provide. Some of NGOs represent special interest groups, while others are more involved in advocacy programs focusing on improved governance. Both the Fiamalamalama and Loto Taumafai schools fall into the second group of NGOs, as special interest groups funded by public and private organizations.
In Chapter 2, I highlighted the critical challenges faced by the Department of Education in the 1960s and discussed the absence of disabled people in government schools. The establishment of Fiamalamalama and Loto Taumafai was an attempt to meet the needs of students with disabilities in formalized schools. The establishment of NGOs for students with disabilities, I contend, shifted the paradigms in the Samoan education system, despite the government’s history of minimal funding and hegemonic practices. The establishment of NGOs with the support of international aid also played a role in the shifting educational pedagogies and praxis.

Even with monies from outside donors, however, the schools still faced issues of sustaining their annual operating costs. Unfortunately, NGOs often have difficulty in implementing sustainable initiatives (Chakravarti, 2005, p. 71). They often suffer from a high cost structure because of the need to set up local country management teams. The use of expatriates on these teams also results in a substantial percentage of the resources reverting to the NGOs’ home countries. Since most of the core staff members are paid expatriates, their temporary employment in another country is a large part of the aid cycle. The implications of such employment factors are unsustainable and disruptive to the NGO continuum of services. For instance, at the Fiamalamalama School, the first round of qualified special education teachers and staff came from the New Zealand Ministry of Education and the U.S. Peace Corps. “In practice per dollar of expenditure, only a small proportion of the resources filter through as direct benefits to the target population” (Chakravarti, 2005, p. 71). Although some money from expatriates living in the community is still going to the local economy, the temporary nature of this exchange remains an issue for the sustainability of the NGO. Moreover, this unequal financial relationship seldom benefits the NGOs on a long-term basis.
Samoan Government and NGOs

According to the International League of Societies for Persons with Mental Handicap, “An NGO is a voluntary society of parents, friends, and clients” (*IH Review*, 1984/1985, p. 11). In Samoa, NGOs were instrumental in developing education for people with disabilities. Tasi, an administrator in the Department of Education in the 1970s, talked about the women’s organizing strategies of the schools. Tasi related, “The main point at the time was equality for all and many of the human resources were mainstreamed [operated by the Minister of Education].” According to Tasi, Samoan independence gave the country a lot of leeway to improve economic and internal development plans. One of these improvements dealt with the process of taking out “low loan funds” or low-interest loans from organizations, such as the Asian Development Bank and the World Bank. Powerhouse international organizations such as United Nations Educational, Scientific, and Cultural Organization (UNESCO) and Japanese International Cooperation Association (JICA) were also instrumental in the development of education, health, and policies. These organizations provided professional staff to operate and train local organizations while also providing technical training, professional support, and funding for equipment and supplies.

As an administrator, Tasi recalled the tough choices that officials in the Ministry of Education had to make, given the limited resources. Due to inadequate funding, the collective needs of the majority often superseded the requests of smaller groups. The logistics of providing educational services and programs were central to the decision making process with respect to the education of students with disabilities (Tasi, personal communication, February 1, 2013). Tasi emphasized that by no means was the government’s intention to dismiss students with disabilities access to education, although in retrospect, this is exactly what happened.
Slowly, things have changed for the better, and the government has made more effort to fund the fiscal budgets of the NGOs. As Faamanatu-Eteuti (2011) argued:

It can be seen that since the work of a number of NGOs in the 1960s, special needs education has received increased attention from both the general public and the government. Although negative attitudes still exist among many parents and untrained teachers, there are a growing number of individuals who stand apart and who are working to improve conditions for special needs children. (p. 72).

The point that Faamanatu-Eteuati made was instrumental to why NGOs were started in the first place—the inadequate programs and services for people with disabilities. The Samoan government’s responsibility to social services for the disability community was not a priority, despite discursive claims otherwise. As some of the co-founders of the schools stressed, the reason why the local government took on funding the NGOs was when funding from international donors was contingent on matching funds. Hence, the local government’s financial involvement with NGOs did not fully emerge until the early 1980s due to community needs and pressures.

Before this time, NGOs were left to their own devices and funding was an individual organizational issue. For example, funding for the Fiamalamalama organization and school primarily came from the New Zealand Society for the Intellectually Handicapped Incorporated (Hereafter IHC New Zealand) in Rotorua, New Zealand. As a result, the Western Samoa Society for the Intellectually Handicapped Incorporated was established in 1979 (Vugler, 1981). After the creation of the organization, the focus shifted to opening a school. IHC New Zealand was instrumental in funding portions of the school building, staff salaries, and school supplies. As this example suggests, funding NGOs is complicated. On one side are donors, who are generally
interested in the expansion of NGO sectors and the development of infrastructures and systems in developing countries. These institutional structures and systems are supposed to improve the quality of life for marginal groups. On the other side, countries outside of Samoa also recognize the business aspects of development assistance.

Although development efforts from overseas-enhanced Samoa’s infrastructure, economic, and political stability, the reality is that international donors still make money on low interest loans and development ventures; thus, colonial economic relations continue to infuse NGO funds in many ways. Likewise, to use Baaz’s (2005) terminology “paternalism of partnership” relates to the identity in development aid, which suggests that aid workers reproduce and thrive on postcolonial representations of identity (p. 170). For example, in Tanzania, the African identity “other” is sometimes understood through a romantic lens and a disparaging one that encompasses the adjectives of passive, corrupt, and dangerous. Baaz concluded, “there exists a contradiction between the message of partnership and the images of Self and partner maintained and propagated by donors and development workers” (p. 166).

Likewise, Cole’s research in the Pacific situated the real pressures for many states granted sovereignty. In the 1960s, Western Samoa was the first state to become independent in the Pacific region (Meleisea, 1987). At the time, Cole was the Research Director for the Australian Program at the National Centre for Developmental Studies (1983), he pointed out:

While independence brought the inevitable trappings of a new nation, such as a new flag, national anthem, written constitution, international bodies, and above all indigenous leadership at the political level, this meant very little within the commercial sector of national economies. (p. 82)
Cole suggested that the reason for this is because relationships established over generations persisted and businesses continued to use these familiar economic pipelines despite government changes. While the new leadership advocated for the need to “localize” and seek out both new markets and sources of supply, many merchants and plantation communities continued to engage in commerce with those offshore partners that they have done business with for decades. More importantly, new economic landscapes opened for the emerging political elite, because aid during colonial times was about the negotiations between “the governed and the governing” (Cole, 1993, p. 82). Despite the change in political regime, very little changed economically, the aptness of how economics functions in this context is an important narrative within this discussion. This broader understanding of the economic status of Samoa in the 1970s alludes to the struggles within the social services and welfare department of the newly independent state. Here, the economic model of neoliberalism, or as Noam Chomsky (1999) asserts is not liberal or new at all. Neoliberalism is a political-economic theory of the 1900s stating that limiting government interference in the operation of free markets maximizes personal liberty or corporation profit. As Harvey (2005) explained neoliberalism is also “political economic practices that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong private property rights, free markets, and free trade” (p. 3). Neoliberalism favors free trade, privatization, and minimal government intervention in business including reduced public expenditure on social services or on the welfare state. Chomsky argued, neoliberalism was created under the guidance of a democratic government, which meant that the government had free range on policies and regulations pertaining to taxes and currencies for corporations to make a profit without many barriers. The non-transparency in how these systems are structured, then,
created deeper state control and regulation of the economy through corporatist strategies within a society. Thus, the forced privatization of these policies has made the ruling elites and foreign investors very wealthy, but also creating social inequities and poverty gaps for the rest of the community. For a developing country such as Samoa, neoliberalism economic models are especially detrimental when funders such as the International Monetary Funds (IMF), World Bank, and the Asia Pacific Fund adopt development modes of operation. For instance, when high interest loans are taken out and funding to social policies are reduced, because the budgets of such nations are in constant debt and crisis of political reform. In talking with Tasi, she shared that Samoa did not have the monetary resources to reform the school system after gaining independence. The country took out “low interest loans” from the Asia Pacific Fund to help with infrastructure reforms and looked to outside funding for assistance (Tasi, personal communication, February 9, 2013). These compounding circumstances faced by Samoa, I contend, also contributed to the hardships faced by the education system that also spilled over to the disability community.

In some countries, “the local impact of development activities depended on the extent to which they became homegrown and an integral part of a country’s domestic political processes” (Chakravarti, 2005, p. 73). In terms of NGOs in Samoa, the ongoing concerns faced by the schools involved securing monies to fund operating costs. For instance, in 1978, Afamasaga Telesia was one of the individuals who advocated for the expansion of a preschool curriculum. She was insistent on finding funding to carry out this goal. She related, “Very little was done in getting the people to organize centers and getting the centers organized [because] there was nothing without funding.” (Personal communication, January 28, 2013)
In fact, there were actually two core under-served groups within the Samoan education system: preschoolers and students with disabilities. Advocates for both groups found that there was more synergy in working together than at cross-purposes. The preschool movement was instrumental in advocating for the education of people with disabilities in formal schools. Yet, Afamasaga Telesia found the entire process of founding the schools (preschool and special needs), “So slow in development because the lack of funding from the government…a lack of interest…a lack of understanding.” (Personal communication, January 28, 2013)

The pressure applied by the organizers to start preschools and special needs programs was indicative of the systemic institutional cracks faced by the community. NGOs such as the Preschool Education, Fiamalamalama, and Loto Taumafai Schools changed the normative structures of educating all students with various learning styles. Hence, the role of securing funding for these initiatives is an essential part of the story of sustainability of the schools. The schools primary source of funding came from New Zealand-based organizations. Thus, one cannot ignore the influence of overseas donors’ financial contributions to the schools over the years.

**Searching for Aid with Preschool Advocates**

In 1978, Afamasaga Telesia wrote to Dr. Munro, Director IHC New Zealand, asking for financial and teacher training support. The preschool classrooms were to be an inclusive space that accommodated two students with intellectual disabilities (with more students arriving daily). As a school administrator, Afamasaga Telesia knew that the preschool teachers and staff needed professional training in special education. At this point, when IHC New Zealand got involved with the preschool association, plans were set in motion to start a branch of IHC (Western) Samoa. The other goal of an IHC branch in Samoa was to bring awareness and services to the
intellectual disability community, as other islands such as Fiji and the Solomon Islands had already established centers with the assistance of IHC in New Zealand. The need was great for an affiliate branch in Samoa specializing in the education of students with intellectual disabilities because no such service existed. Therefore, in September 1979 the Western Samoa Society for the Intellectually Handicapped Incorporated (IHC in Samoa) was established officially with the financial backing of IHC New Zealand (IHC, 1989).

The preschool organization, under the leadership of Afamasaga Telesia, also started applying for grants from organizations and agencies in Canada, Belgium, New Zealand, and the Australian High Commissioner’s Office (Afamasaga Telesia, January 28, 2013, Personal communication). Subsequently, small amounts of funding by all these agencies came in and used to find a permanent location for the preschool. The preschool first asked the Protestant Church to allot one of their properties in the town area for the relocation of the school. The Church denied the request and Afamasaga Telesia proceeded to ask the Western Samoa Trust Estate Corporation for Land (WSTEC) for government lands that could be made available for the relocation of the school. After going back and forth between the Protestant Church and the WSTEC, Afamasaga Telesia received permission to use the land located in the village of Sogi. A noteworthy part about the 3.25 acres of land granted for the preschool was that it was seawater swampland. The preschool organizers were ecstatic to get a “place” to relocate the school. However, the next task was to raise additional funds to fill in the swampland. Again, the women organizers came together and worked out a plan to get the task done. This labor of love brought together allies from the disability community, the church community, and locals who believed in the cause. The women’s social and economic capital facilitated these relationships facilitated by within the local community.
The Case of Aoga Fiamalamalama

Gathering financial support for the schools (preschool and Aoga Fiamalamalama) was a collective effort. To create Fiamalamalama, a school for students with intellectual disabilities, forging connections through the efforts of the school organizers, who wrote grants and sought donations and support from international aid organizations. The members of the Asian and Pacific Action Committee (APAC) were people who have experience and are committed in the two areas of “disability (formerly called handicapped) and development”. Therefore in 1979:

J.B. Munro visited Western Samoa to provide encouragement to a small group of parents and interested people keen to establish a local IHC. In September 1979, Western Samoa IHC was born, and when Laureen [APAC Liaison Officer] visited several months later, a small building had been secured which would serve as IHC’s school for a number of years, fundraising [was] begun, and a teacher was employed (funded by APAC).

Training opportunities in Fiji and New Zealand were taken up and educational equipment purchased. In 1980, affiliation with IHC in New Zealand was established. (IHC, 1989, p. 12)

The above excerpt shows the initial collaboration between the women organizers and IHC New Zealand. This exchange also signals the far-reach that IHC New Zealand had in the Pacific region with establishing schools for people with intellectual disabilities. IHC predominantly focused on the education and welfare of people with intellectual disabilities (also referred to as severely handicapped). IHC in Fiji was one the first establishments in the Pacific region; the school and Centre in Fiji, established in 1978 (IHC, 1989, p. 12). As IHCs developed throughout the region, many of the staff and educators went to Fiji or New Zealand for further professional development and trainings. For example, the groups of teachers and staff for Aoga
Fiamalamalama went to New Zealand and Fiji for workshops and certificate trainings in curriculum development and behavioral management (Sua, personal communication, January 28, 2013).

**Donors’ Responsibilities**

In 1979, the commitment of the IHC New Zealand (NZ) and the IHC Western Samoa continued to strengthen in terms of establishing a new centre. The NZ Committee established the Asian and Pacific Action Committee (APAC), a standing committee of the NZ Committee, formalized the support group given to the Asian and Pacific countries linked with NZ. As stated in the IHC Newsletter, APAC’s major contribution to Western Samoa IHC was the purchase of land for the new “Aoga Fiamalamalama Centre” and school. Thereby, the use of funds of the Western Samoa IHC officially led to the opening of Fiamalamalama School in 1979, while the Aoga Fiamalamalama Centre was officially opened in 1985 (IHC, 1989, p.12). In addition, APAC funded the position of Administrator of Western Samoa and responded to expressed needs.

This close relationship fostered ongoing dependency on international aid and external expertise. Crossley and Holmes (1999) reminded us of the relevance of aid to local needs. They suggested, “If the distinctive cultural and economic needs of small states are to be met effectively… [global] agendas need to be well balanced with local priorities” (p. 52). More aptly, these priorities need to include the educational structures and processes of indigenous knowledge systems, in “order to develop transformative, empowering and culturally appropriate teaching and learning environments” (Makuwira and Ninnes, 2004, p. 243). For example, Ravuvu (1988) cautioned us about the problems in rural development and modernization in the
village of Nakorosule, Fiji and the decline in self-sufficiency and self-reliance, as some of the unforeseen negative effects of development. Ravuvu anticipated an increased loss of control over one’s own destiny and resources, which put rural Fijians in a position of dependence on outside resources and on those few who ultimately control the economic power of the country. Although it is hard to gauge and quantify if local priorities were taken into consideration, what is apparent is the close co-dependent relationships between the NGOs and the international donors. Noticeably, the funding and staffing for Aoga Fiamalamalama came from New Zealand. These dynamics attributed to the negotiations and compromises between the organizations on resources and long-term goals for the school.

The Case of Loto Taumafai

The influence of international aid on Loto Taumafai’s case is slightly different compared to the preschool movement and Aoga Fiamalamalama. Loto Taumafai was established in 1980 after the preschool and IHC were in operation. Given that it was a collaborative effort by the founders of the previous organizations and their allies, its conceptual organization was also easier. Since Fiamalamalama had already laid the infrastructure and groundwork, Loto Taumafai was at an advantage through its familiarity with existing donors and the local government. As Fiasili, the first president of Loto Taumafai suggested, our “financial standing is good” (Keil, n.d., Loto Taumafai National Society for the Disabled, Annual Report by the President). Even though the ongoing challenge for Loto Taumafai after its conception was finding monies to sustain its operational costs. For the first two years, funding was consistent for providing programs and services. Loto Taumafai was more equipped and organized than Fiamalamalama at its establishment for various reasons, including the “seasoned” experiences of the founding members of the schools and their already established network of supporters, along with local
government funding. What is apparent is the relatively comfortable position that the organization was in, making the need for funds less pressing than it was for the preschool and Fiamalamalama school founders. Thus, the influence of international aid on Loto Taumafai was a double-edged sword. The organization benefited from the previous experiences and networks of its founders, but on the other side, the leadership and school staff also became somewhat complacent in their struggle to continuously fundraise and seek grants. According to a monthly newsletter, Loto Taumafai Society was effectively founded on September 30, 1980. As Fiasili Keil (1981), the President, shared in her monthly report:

Our first major tasks were to set up ourselves physically and to establish the parameters by which we would operate as an umbrella for all disabled groups. The first objective we achieved in relatively good time and our office in the [village of] Matautu-uta has operated effectively, even though its full capacities have not always been utilized. Funds were fairly readily secured, primarily from Foundation of Peoples of the South Pacific, the New Zealand High Commissioner and the Australian High Commissioner, and by and large, the financing of our activities has not so far been a particular problem for us. (p. 1)

Given the ample sources for funding, Loto Taumafai was in good financial standing. However, there were other challenges, such as finding a permanent location for the school. According to Fili, after a couple of years of the school being at the village of Matautu-uta the school was asked to relocate because the owners of the property were renovating the premises (Fili, personal communications, February 5, 2013). At this point, Loto Taumafai turned to the local government for assistance in finding land to relocate the school. After several years of
negotiations, Loto Taumafai transferred to government land in the village of Moto’otua—where they continue to reside today.

**Finding Space**

**Free Hold Land and Government Land**

The subject of land in indigenous communities is a complex and sensitive one, and the stories about the school building sites are especially important in understanding values, cultural hierarchies, and attitudes toward the disability community. Typically, in the Samoan context, customary land is land that belongs to the nu’u or village. It does not belong to one person, and the villagers and their extended clans are the caretakers for the land. The selling of customary land for monetary gain by anyone cannot occur without the village’s consent, ensuring its transference to the next generations (Meleisea, 1987). Land considered “free hold” pertains to land in various villages throughout the island that are free to sell and available for purchase through monetary exchanges. Individuals who had the economic capital often purchased free hold land. Conversely, “government lands” usually referred to land owned by the local government and used by government agencies, leased out to businesses or private citizens, or allocated for farming, plantations, schools, and conservation. Therefore, the building sites for the preschool and Loto Taumafai schools were located on “government land”. However, Fiamalamalama School deviated from this course and bought free hold land.

Established in the early 1980s, the initial idea that the founders of the school had was that Loto Taumafai was to combine all the disability organizations or as Fili related, “supposed to be an umbrella organization for all the societies” (Fili, personal communication, February 5, 2013).
Unfortunately, this idea of combining all the organizations did not pan out due to various disagreements among the organizations over funding, operational logics, and leadership agendas. By October 1983, the decision by IHC and Loto Taumafai was to obtain separately land. Tensions remained unsettled in terms of finances and support among the representatives of each organization.

According to Lupe, IHC Western Samoa wanted to also collaborate with the government schools and Fiamalamalama approached the Minister of the Education for the possibility of using some of the land at Samoa College [local high school], located on a compound of 15-20 acres. As Pat Marfleet, the Liaison Officer of IHC related, “previous approaches to this department have met with a negative answer, but we feel it is worth another try” (The Western Samoa Society for the Intellectually Handicapped Inc., 1983, p. 1). It was at this point, that IHC made the decision to purchase land without the assistance of the local government. As Faatonu Faletosee (1983), the president of IHC Western Samoa, suggested in her arrival (annual) report:

Since last year, we have had numerous discussions/negotiations on this subject [of land for the school]. It has become a perplexing problem to the Executive Committee too, hence our decision to divorce ourselves completely from further and future negotiations of Alafamua land, and seek permanent premises elsewhere, due mainly to too many hassles and unconfirmed results with the WSTEC Land Board officials. (p. 1)

The women organizers corroborated this story by stating that after the last failed meeting with the Ministry of Education and the Blind Society (NGO), the women organizers were frustrated and made the decision to figure out a way to purchase free hold land for IHC. Here the idea of buying free hold land allowed the women organizers autonomous range to operate the school
logistics as a private organization. They were able to alleviate the looming fear of the
government intervening in the school affairs and relocating the school anytime by buying free
hold land. Locating the school on government lands also came with a responsibility of adhering
to government policies and mandates. The women realized that in the end their choice of buying
free hold land exempted the school from political maneuverings and obligations. When it was
time to find land, again, Fiamalamalama turned to IHC in New Zealand for financial assistance
to accomplish this goal. On December 23, 1983, the New Zealand IHC and APAC responded to
Marfleet’s letter regarding the challenges of securing a location for the school. With the support
of APAC, the following agreements arrived at IHC Western Samoa:

In the event of securing an option on land or a building, APAC would be prepared
to grant you NZ$10,000, and would apply on your behalf to NZ Foreign Affairs
subsidy scheme to voluntary agencies for a further NZ$10,000. The latter you
will appreciate is not assured, but well worth a try. Such applications usually take
a couple of months. (Munro, 1983)

The grant for purchasing the land did not cover half of the cost. According to the Estate Agent
and IHC documents, the price of a half-acre land with an existing building would have cost them
$50,000 tala or Samoan dollar12 (Marfleet, 1983). Throughout this time, the women organizers
continued to inquire about properties for sale in town for the school. Because the location of the
school would be “in town” however, the founders expressed concerns that most of the students
living out of the town area would not attend school regularly. Finally, a great deal came up in
the village of Alafua, about 10 minutes from the town area. Lupe related that the purchase of the
land where Fiamalamalama now resides came from a close relative that was moving off island.

12 The amount of $50,000 tala is comparable to approximately $20,000 U.S. dollars.
After securing the purchase of the land, the next task was to raise money to build the school buildings and purchase a bus for the school. The following is a quote regarding the communication exchanges between the IHC in New Zealand and Western Samoa. In a letter to Mrs. Munro, Pat Marfleet (1984), an APAC Admin/Liaison Officer wrote:

On behalf of the Committee, I wish to thank you all at APAC for the offer of a grant of $10,000 towards the purchase of land. During the holidays we found what we thought was an ideal piece of land at the right price, but on checking with the Lands and Survey Dept. We were disappointed to find the area was not as large as the owner would have us believe. We recently tried advertising in the paper, without luck, so we are back to spreading the word and hounding the Estate Agent. (p. 2)

Marfleet’s report stated that the school received the grant but could not close a deal on the land they intended to purchase. As the women organizers clarified, this particular land was smaller than what was advertised to them. Before purchasing the land, the women organizers hired a land surveyor to measure the property. The other reason they did not purchase this land was that it was far from the town area, making it difficult for students to attend. Thus, the work of organizing Fiamalamalama did not end with purchasing land for the school. It continued through the planning and building process for the facility itself. Another tension was the organizations’ physical location. By 1983, the discussions of finding land to build the schools for Fiamalamalama, Loto Taumafai, and the Blind Association were well underway. Actually, the initial plan was for the three organizations to request government land from the WSTEC, which would house the organizations. Unfortunately, none of the negotiations among the various agencies
worked out. The answer to the request to find land to relocate all the organizations was denied, and Loto Taumafai and IHC approached the Blind Association to see if they could share their facilities:

25th October Meeting between Lototaumafai, IHc [sic] and the secretary of the Blind Assoc [sic] as the answer from WSTEC had been the same as in the past it was decided to approach the Blind Association with regards to sharing the facilities in Alafamua. The secretary felt that the time was now right for this approach as far as the Blind Assoc. Committee were concerned, but was not sure of the reaction of the blind people themselves. (Marfleet, 1983)

Unfortunately, sharing facilities with the Blind Association did not pan out and the women suggested that personality differences and organizational goals were some of the biggest reasons why the organization never collaborated. At this time, the preschool location in the village of Sogi was also operating and servicing more students. The next task was hiring a permanent head teacher and an assistant teacher to oversee the operations of the school. Again, the IHC New Zealand took the lead in funding the salary of Sierra Vili, head teacher. The annual salary of the head teacher was NZ$1500.00 and this amount was paid for by APAC in 1982, according to Administrator/Liaison Laureen Munro’s letter to IHC Western Samoa. (Solora, 1982)

By the mid-1980s, one head teacher and two teaching assistants were hired as staff members. The IHC in New Zealand paid for the salaries of these educators. Following the opening of Aoga Fiamalamalama, several founding members also helped with the organizing of Loto Taumafai School. From the women organizers’ stories, it seems that several factors sustained the operations of the schools--community support, individual family support, and the dependence on funding from abroad. Fili related, “We used to do workshops, they were
wonderful workshops. Sometimes people in town would say, make us a chair, a table like this and the kids would make them and we would charge them. And the money went back to the school. Put it back all in the school.” (Personal communication, February 5, 2013)

Additionally, the role of individual family donations to the schools, international aid, and gifts from the local organizations also supported the schools in providing services to the disability community. Organizations such as the Rotary Club of Samoa, Catholic Charities, the Seventh-Day Adventist Church, the Church of the Latter Day Saints, and the U.S. Peace Corps were instrumental in the maintenance of the schools, paying for the students’ medical care, donating food, and classroom supplies, and bringing medical professionals to the island (Sisi, personal communication, February 7, 2013). Even with these difficulties faced by the women organizers, every participant related to me that if they had to organize the school all over again, they would do it in a heartbeat.

**Partnership between Schools**

The relationship between Fiamalamalama and Loto Taumafai was not a cohesive one. Sina, one of the founders of both Fiamalamalama and Loto Taumafai, tried very hard to foster a collaborative relationship between the two schools, as they were serving similar populations and goals. Loto Taumafai’s mission was slightly different from Aoga Fiamalamalama. First, they intended to serve different student populations. When Fiamalamalama was established, the intended school population was students with intellectual disabilities, whereas the intended population for Loto Taumafai was for students with physical disabilities. However, as each school continued to enroll students, many students with various physical and intellectual disabilities “showed up [to Aoga Fiamalamalama] and we couldn’t turn them away” (Sisi and Sina, personal communication, January 13, 2013). The two organizations also did not agree on
how they should function politically and logistically. Politically, some of the women organizers conveyed that people in leadership positions at the NGOs did not have long-term goals for the organizations and usually planned for the school year. Logistically, some of the NGOs were content with the minimal funding received from the local government to function as an organization. Contrastly, the women organizers, wanted the local government to give more funding to the NGOs. Nevertheless, the two schools continued to work together in some respects. For instance, the schools referred students to each other, depending on the student’s educational needs. According to some of the founders, most of the tensions between the two dealt with how the two agencies operated and accounted for aid monies. Lupe, one of the Fiamalamalama organizers, said, “We had a good treasurer; Maxine was really mean--she wouldn’t give us any of the money once we gave it to her. She kept the books and kept them good. She kept them really tight. The money that was raised [or received] always went to what it was raised for.” (Personal communication, January 23, 2013) Because grant monies often came in large sums, the challenge was to spend these funds on school-related expenses and also itemizing expenses with receipts and a systematic accounting system. The two organizations had different levels of experience and expertise in dealing with the financial aspects of the schools. As Lupe suggested in our conversation, “a good treasure” and volunteers were key to Aoga Fiamalamalama’s success.

**Fundraising for the Schools**

A persistent theme throughout the women organizers’ stories points to their ongoing fundraising efforts to sustain the schools’ operations. Fundraising often took the form of formal events organized by the founders, with the local community contributing. For example, in August 1979, a Charity Premier for the New Zealand film Sons for the Return Home helped to
raise money for the schools. The film, based on the novel by Samoan author Albert Wendt (1996), was about a young Samoan boy who went to Wellington, New Zealand with his family when he was five years old. The character grows up in the Taupo region and eventually goes to Victoria University, becomes a teacher, and returns to Samoa to teach in secondary school.

**New Zealand Private Organizations**

The proceeds from the five hundred tickets to the premier yielded approximately $10,000 (New Zealand (NZ) dollars), which was donated to the Intellectually Handicapped Children (Ron Majors, Intellectually Handicapped Children’s Society, Epsom Auckland). According to correspondence with the Consulate-General of Samoa, part of the proceeds from the film premier was to “be donated to launch the proposed Society for the Intellectually Handicapped in Western Samoa and the balance either to the Society for the Intellectually Handicapped in Auckland [or] who[ever] needs it more” (Vaimasan’u Apa, 1979, p. 1). In the letter’s closing section, the General-Consul Apia wrote, “Once again, I reiterate our full support for this project. New Zealanders are raising funds to help establish a centre for the intellectually handicapped children in Western Samoa. The New Zealand Film Commission and an Auckland film company, Kerridge Odeon, have announced they are holding a world film premiere soon to raise funds for this purpose” (*The Observer*, 1979, p. 13).

**Independent Donors**

The monies received from these organizations went directly to the operational budget of the schools. Although these were overseas organizations, they were regular donors to the schools and the schools gladly took their money. As Sina related, “People were generous and we got money from people that we did not know” (Sina, personal communication, December 22,
Monies from high-profile fundraising events often paid for staff salaries and operational costs (school supplies, electric and water bills). The school founders related that much of these funds did not always cover all of the expenses for “running” the school. At the time, students attending both schools were required to pay $20 tala (Samoan currency) for a year of tuition fees. However, some students could not afford to pay, and therefore, fundraising and charity donations became the primary funding source for the schools’ budgets. The women organizers were committed to educating the students, and they were clear in their interviews that despite financial adversities within the schools, they did not turn away any students because they could not afford the tuition fees.

One of the main ways that the schools recruited students was through newspapers ads, television commercials, public announcements on the radio, and community outreach by the staff. The local newspapers and television networks also played a role in advertising fundraising events to the wider community and inspiring parents to bring their children to school. These efforts increased awareness of the educational needs of students with disabilities and of the schools themselves. The schools also maintained public visibility through participation in festivals and fundraising events. As one advocate related, people often said, O tamaiti lea e lelei mafau'au [These are the kids with good brains]. Yet, despite increased awareness, ableist attitudes persisted in relation to mainstreaming students with disabilities in government schools. Because of parent and teacher advocacy, several students from Loto Taumafai School (such as Lisa featured in Chapter 6) were able to also attend government schools. In all of these ways, the schools were increasing disability awareness on the island. Of course, progress was not always easy or even. In an annual report, for instance, Fiasili noted, “The first full year of the Society’s operation have, I feel, been encouraging and, to a degree, rewarding, although, perhaps
inevitably, also full of all the frustrations, which new bodies must face if they are to find their feet” (Keil, 1983, p. 1). In some ways, however, the communities in Samoa and New Zealand engaged the issues of educational exclusion and collectively found solutions. Along with the fundraising events, IHC (Western) Samoa continued to ask the local government for assistance. The founders wanted:

To discuss with the government and the appropriate Government departments the issue of how to place the Society’s funding on a more reliable and consistent basis. The funding formula used in recent years, which has been based on a real growth rate assumption of three percent per annum, has been most unsatisfactory in view of the fact that the Society’s actual growth rate has been substantially in excess to this figure. Because of this it has been necessary to negotiate special financial arrangements from time to time including the advance payment procedure for subsidy money. (Wills, 1986, p. 1)

With such inconsistent school funding, fundraising events were perpetually being organized to make up for the lack of funds. Fundraising events included a “Can-Can” event, in which the attendees dressed in dancing attire and raffled off donated items. For instance, a founding member’s spouse was a gynecologist and offered to raffle off his services. Another founding member’s family had a plumbing shop and donated restroom supplies, such as a toilet and sink (Lupe, personal communication, January 23, 2013). Another founding member shared her experiences with fundraising for the preschool. She said, “Those days, e fai fai, i’a tu’u, and we went to fundraise for our wages” or “Those days we work and work and then stopped and went to fundraise for our pay” (Afamasaga Telesia, personal communication, January 28, 2013,).
Dance Group. In addition, the a’u siva or Polynesian dance group that toured American Samoa and Los Angeles also contributed to fundraising. This group did not last long, because the manager of the group hired by the preschool had a dispute with the school staff regarding the monies spent and received. Later on, the preschool raised enough funds to purchase a Ferris wheel and a merry-go-round from Fiji (Afamasaga Telesia, personal communication, January 28, 2013). A carnival was set up at the village of Sogi and every weekend the teachers worked overtime to staff it. Afamasaga Telesia remembered bringing her family to the carnival every weekend, as this was the only time she could spend time with her children and spouse. They bought the carnival equipment outright so that the income could pay for the school’s staff salaries and overhead costs. Fili remembered one event the school had called “Have a heart for Loto Taumafai”. As she described it, “We give badges saying have a heart for Loto Taumafai, and they give us money or whatever thing they want to donate, and that was one time a year and we made a lot of money with that” (Fili, personal communication, February 5, 2013).

Theatre Group. Loto Taumafai also had a theatre group called Silent Worlds primarily made up of the deaf students. Fili shared that the Silent Worlds theatre group performed at a lot of government events, private company functions, and different events throughout the island. The group was under the guidance of a New Zealand performing arts teacher working at Loto Taumafai, who mentored the deaf student’s theatre performance (Fili, February 5, 2013, Personal communication). Sadly, when the teacher returned to New Zealand, the theatre group disbanded.

Another fundraising event the women enjoyed reminiscing about is the “Hold Your Boss for Ransom”. This involved “bosses” of various agencies across town who agreed to be held for “ransom” for the Fiamalamalama fundraising. The school organizers “kidnapped” the boss of an
organization and left a note for his/her employees with instructions telling the employees where they could find their boss and the amount of money that the organization must pay for his or her return. This event was fun and the school raised a large sum of money. As Lupe said, “it was a lot of work, but we had a lot of fun”.

The women organizers were also assertive in asking government officials like the Prime Minister (PM) for resources. Lupe and Sina recalled one time when they went to the PM’s office to ask for a donation. They both gave a long, drawn-out speech (Samoan protocol or a gesture of respect) about the Fiamalamalama School. After an hour of indirectly asking the PM for money, Lupe remembered saying to him, “Look, we are here to ask you for some government grants to support our school, we are drowning. Please help”. The result was a commitment of a small grant for $10,000 that awarded to the school the following year (Lupe, Personal communication, January 23, 2013). As stated, Sina and Lupe were careful to emphasize to these officials the meticulous bookkeeping that their treasurer did in balancing their budget. They delighted in telling me that their organization was the only one that submitted a balanced budget report to the Minister of Finance every year. They believed that the school received annual funding because of their careful stewardship and accounting of donated funds.

By the early 1980s, the preschool had also grown to include 25-30 students. Unfortunately, the money made from student fees did not cover all the costs of running the preschool. Since some parents could not afford to pay for school tuition, this trickled down to other aspects of the school, especially paying for the staff’s salaries. The schools often experienced high turnover of staff as a result. Yet, when times were tough, a few committed teachers, staff members, and women organizers worked without pay in order to maintain the preschool.
Community Allies. In addition to these fundraising events and requests to government officials, organizers also made good use of their connections with local officials, even persuading some high commissioners from New Zealand and Australia to permission to use their homes for fundraising events. As Lupe stated, “We would go and raise the ground [praise them], and we would ask for the use of their residence for fundraising. Because in those days, people would pay to go to the high commissioner’s house”. Other fundraising events at the high commissioner’s house included a Persian-themed night, where a belly dancer from Tahiti came through a donation from the Polynesian Airlines. They were also able to get some “French bread…that the pilots [brought] in from Tahiti”. The colonial politics involved in transporting a female belly dancer by airplane to Samoa from Tahiti, importing French bread and cannot be ignored. Objectifying women’s bodies for entertainment and profit played into the colonial narrative of indigenous women as property and objects “free” for taking. This example also reifies the construct of Samoan nationhood, based on Western notion of nation and democracy, which has taken on a patriarchal structure that undermined Samoan women’s traditional autonomy and authority.

This example is in many ways about indigenous politics, settler social class, and multiple forms of privilege used to move “brown” bodies across the Pacific Ocean as commodities, and thus offer another glaring reminder of imperialist interests in the region. At the same time, this illustration also indicates how Samoan people empowered themselves as a group in relation to the dominant society (Denetdale, 2007). The women were very proud of their networks: “[We] never paid for anything because we would ask the police [department] for their jazz band to play at the function. We had the high commissioner’s house, drinks [alcohol] from the pilots who
Generous donations by community members also brought the women together for a cause. The founders of the schools were methodical in how they prepared for fundraising events. For example, Lupe suggested, “You always pre-sold [tickets]. It didn’t matter if it rained like hell. I didn’t like to have raffles throughout the night, I said you pay for a ticket and you go in have dinner, a drink, and that was all a part of the ticket. You had entertainment and that was a part of the night”. Another effective protocol was that after each event, the women would send handwritten thank-you cards and deliver them to donors with flowers or a small gift to show their appreciation. More importantly, the women exercised integrity in regards to the donated items. For example, if any of the items remained after the event such as drinks or whatever donated for the event, the women would return them to the donors. In essence, the idea was that by returning unused items to the donors, they would be more apt to donate again.

As these examples show, fundraising events provided a major source of funding for the schools, supplementing the grants from international agencies. No source of financial support could be taken for granted, however. Sisi shared a time when the school “lost” a grant from the German government. She said, “They gave us 5000 Euros a year. The only reason [we did not lose those funds was] because I did everything…breakdown the costs every month and report to them and what we did for our teachers. I think when T [another administrator] took over; she didn’t like to do the three-month report. [So,] we didn’t get it [grant] anymore”. Sisi’s comment pointed to one of the other pressing problems that most of the NGOs encountered, namely the constant changing of staff and leadership. The ongoing frustrations of maintaining staff, teachers, and school administrators continue to this day. The need for consistency and
professionalism also affected the entire continuum of grants, services, curriculum, and instruction. At Fiamalamalama, for instance, besides the core founding members of the school, there were only two staff members still around from 1980—a teacher and the bus driver. Unfortunately, most of the previous staff members either moved on or passed away.

**Contributions from Local Organizations**

Local agencies such as the Rotary Club also collaborated with the schools. The Rotary Club of Apia, in particular, shared a special relationship with the Society since its inception (Keil, 1981). The Rotary Club was an organization comprised of men from the local business sectors and various professional organizations. Since the Rotary Club was a predominately-male space (women not allowed), school founders who had spouses involved in this club elicited their support for the students. For example, Sisi, whose partner was the chairman of the Rotary Club in Apia, shared a story about a student at Fiamalamalama who had a severe hearing impairment. The student needed a medical procedure in New Zealand to alleviate the pressure in his ears. Unfortunately, the student’s family did not have the resources to send him. Sisi wrote a proposal and her partner presented it to the Rotary Club. The club raised the monies to send this student and his mother to New Zealand. Happily, Sisi shared that upon the student’s return from NZ, he attended government school and as an adult found a job, got married, and had a family.

The Rotary Club in New Zealand also financially supported students at Loto Taumafai who needed medical procedures. In addition, they provided equipment (paper, projector, art supplies) and services (repairs for the bathrooms and classrooms). Both schools benefitted from the Rotary Club because of the relationship the women founders forged with this organization. Occasionally, other New Zealand based organizations helped the Society or Fiamalamalama. This information often circulated in the local newspaper: “Lile Danes, an administrator of
Blenheim Branch of the New Zealand Handicapped Society was here last week to present the local society with equipment including records, a Polaroid camera, and books” (no author, 1980, p. 11).

With such news, people in the region were also inspired to help. Local organizations such as a young men’s association called Tama Samoa raised funds to give to various charities. One newspaper article stated that, “Some of the future recipient organizations Tama Samoa has in mind are the Western Samoa Intellectual Handicapped Association, the Disabled Society [Loto Taumafai], Pre-school association, lepers and retarded at Apia National Hospitals” (no author, 1980, p. 2). The Lions Club was another local club that supported the school and its students. An article in the local paper stated, “The Lions Club has paid for half the fare of a child with a brain tumor to enable the child to have medical treatment in New Zealand. The other half is being paid for by the government” (no author, 1977, p. 2).

Other supporters of the school included the Westpac Bank, which funded the petro or gas for the van used to transport the students, and the Japan International Cooperation Agency (JICA), an Official Development Assistance (ODA) office established in 1974 by the Japanese government, which funded part of the cost of construction for the school. Fili recounted that JICA provided funds to Loto Taumafai for the school building and a trained teacher to work with the school for the entire year. In addition, AusAid from Australia provided money to buy furniture for the school. The most difficult part of relying on these kinds of donations and financial support was finding creative ways to sustain these programs and keep the wider community’s interest in the school.

Ongoing fundraising efforts were also essential to the development of Loto Taumafai as a recognized educational institution. An annual report of the school stated, “We have formed
useful links with appropriate organizations in New Zealand, Australia, the United States of America and the United Nations System” (Keil, 1981). The United States relations to the schools mainly dealt with the use of Peace Corps volunteers to staff the schools. JICA was also another organization from Japan who provided trained special education teachers. According to Rosa, a parent advocate, the NGOs often have to turn in an application to the Peace Corps or the JICA offices in the village of Apia for a special education teacher. Continuity of keeping trained staff in the schools was one of the struggles that resulted from relying on volunteers at the schools. As Rosa related, after a term of one or two years, many of the Peace Corps and JICA volunteers left their post and returned home. Finding replacement staff was a challenge that both schools faced on a continuous basis. The impact of having temporary aid, volunteer staff, and intermittent school supplies created an arduous and ongoing responsibility that the women organizers dealt with on a daily basis. They also influenced the curriculum and educational aspects of the school discussed further in chapter 5.

Thus, fundraising was something that the school continued to do creatively throughout the year. In addition to local organizations and events, funds also came from charitable organizations such as the Lindnal Mission and The Blind Society, in addition to the New Zealand government, which were all instrumental in providing staff to the school. For example:

We …got help from New Zealand, in which we applied for teachers with certain skills and sometimes principals…We had a principal; it was part of the New Zealand government funding. [Educators coming to Samoa were] usually retired people…New Zealand volunteers and they come for 2-3 terms and the organization [New Zealand government] paid these people to come. (Fili, personal communication, February 5, 2013)
Another source of funding for the school came from individual donors from overseas. For instance, one woman from Norway comes every year, bringing school supplies, and whatever else she can fit in her luggage. “It is amazing how people are helpful… she brings money and a few resources [school supplies like pencils]. And people come from all over the world and bring stuff. I guess people who have interest in disability”, shared Fili. Besides money, donations of professional services also came to the school. For example, “We had a few medical doctors on our board. An eye doctor, a physiotherapist…” and many of these people continued to help the school for quite a long time. These funding practices, minimum collaborations among the organizations, and the lack of resources provided by the Samoan government contributed to the divisions among the NGOs. Lupe shared, “Some people had a different agenda, and so there was not a fair division of where the funding went.” Throughout my conversations with the women organizers, the theme of how the aid monies were spent, accounted for, and the shared resources of professional staffs became a point of contention among the various schools and associated organizations.

Fili was the former President for Loto Taumafai for twelve years. She remembered the time when no one wanted to be under the umbrella organization, Loto Taumafai National Organization. She believed that, “They [the other organizations] wanted to do their own thing…for some unknown reason it never took off”. Another reason for not wanting a link to other schools was the competition among the schools in applying for grants and government support. As Fili stated, “Sometimes the information about grants and monies from overseas agencies are not related to them until the deadline is passed.” Of course, this caused a lot of tension among the schools, pertaining to access to funds and accountability for where the monies were spent.
Funding and donations from overseas was central to the operation of the schools. The New Zealand Ministry of Education and the AusAid from Australia were instrumental in providing aid, teachers, grants, and professional trainings to the schools. JICA was also very influential in providing skilled laborers (engineers, electricians, builders) to construct the physical structures of the schools (Sisi, personal communication, February 7, 2015). Despite the generosity by outside organizations, fundraising for the schools continue to be an ingrained ritual. This points to the limitations of the charity model, because there was never enough money or resources to keep the schools afloat. Here, the implications of the schools not having concrete systems of support or the kind of infrastructures in place that government schools could rely upon created recurring difficulties for the organizers.

**Moving Forward**

The disability community, by the mid-1970s, was slowly gaining momentum in petitioning for support to establish educational institutions. Given the struggles in the government schools to provide services for their students, the desire of people with disabilities to be also included in schools, to say the least, was not a priority. As some of the founders related, people who did not support their mission often asked questions such as, “Why are you funding, fundraising, and organizing for this organization?” Other prominent members of the community would also make comments such as, “Well, you know the deaf they are just deaf. You know the blind they are just blind, but this [students with intellectual disabilities] there is just no hope” (Lupe, personal communications, January 23, 2013).

The negative sentiments from prominent members of the community about educating people with disabilities did not deter the organizers. Lupe, one of the founders for Fiamalamalama suggested, “I guess when you are from a developing country, they try to think of
where the most can be done. This was sort of a luxury.” Despite the half-hearted support and negative attitudes that people in leadership positions had toward their cause, the women continued to advocate for their students by contacting international organizations for financial or professional development support. The school founders understood that financial support from the Samoan government would be limited, so they actively explored their options of funding sources from Australia, Canada, Japan, and New Zealand. Thus, the luxury of not educating students with disabilities was something that the women organizers could not afford and would not concede. It was imperative that all students including those with physical and intellectual disabilities receive a quality education.

Throughout the process of fundraising and applying for funds, a small group of students began to meet as a class; teachers from the preschool and some of the women organizers came together to work with the students. As Sua, one of the founding teachers of Fiamalamalama recalled, “sometimes we worked long hours without pay.” The main point here is that the schools were already in progress even before funding arrived from outside agencies. The school founders’ had goals of educating students’ regardless of government, community support, or popular opinion.

An interesting part of this story was that the fundraising events for the schools intensified after the founding of the schools, meaning that even without funding the school continued. For example, the six students, known as the founding students of Aoga Fiamalamalama, continued to attend school by going to the preschool and later to a small fale o‘o (small hut house) in the yard of one of the student’s family. This part of the story shows the motivation of the women organizers and their allies to educate students with disabilities regardless of material resources. To be clear, having money or funding was an important aspect of the schools’ formation and
mobilization. However, it also meant that the lack of funding for schools like Fiamalamalama and Loto Taumafai was not an excuse to discourage the attendance of students with disabilities in formal schooling. As Sua recalled, *Ia o le alofa mai a le Atua ia matou* (or It was God’s love for us) that drove our work and our deeds (Personal communication, January 28, 2013.). Sua’s comment also highlights the Christian values that most of the women organizers subscribed to and often referred to as the source of their motivations and blessings for the work they were doing.

In addition to struggles over funding, understanding the long genealogies of land appropriation and economic development by colonial governments is relevant to understanding larger social and political contexts of the schools issues over securing land. Native scholars have articulated the significance of land for Native Peoples. For instance, “Pointing out the sacred dimensions of the relationships between people and land, many Native people see the land as a living entity that has provided sustenance for all living beings, and is therefore known as Mother” (Denetdale, 2007, p. 162; Goeman, 2008; and Vine, 2003). As with most colonial governments, to imagine that a country is empty space with only wilderness and fauna makes it an acceptable locale for occupation and violent systems of oppression. These perceived images of “uninhabited” land justified white settlers’ arrival and governance over the excavation of natural resources or the strategic location of occupation. Mostly, these logics lead to the dismissal of indigenous peoples and immigrants from the non-Western world already residing on these lands. For Samoans, similar disenfranchisement of indigenous people, land and culture are a part of their story. In the late 1800s the German, American, and British commissions economically invested in copra and cacao plantations, as well as shipping ports for whaling and merchant routes (Meleisea, 1987). The Samoans and the colonial groups had vastly different
understandings of land, cash economies, and governing bodies. Hence, conversations about free hold land, government land, education, and fundraising are reminders of these complex relationships with histories and structures that continue an exchange in an indigenous context.

Conclusion

Asking difficult questions about the logics of goodwill and charity and its historical role in “helping” the disability community, especially in developing countries, are necessary conversations. Whether these forms of help manifest in telethons, grant competitions, loans, or charity--we must ask who really benefits from these so-called acts of kindness. Australian-based scholar, Meekosha (2011), offered a southern theory of disability and argued that “the dominance of the global North in the universalizing and totalizing tendencies of writings about disability has resulted in the marginalization of these experiences in the global South” (p. 667). The experiences of people in the global South intimately connect to the global economy and external control of resources like land, sea, minerals, wars, and economic resources. The role of the global North in “disabling” the global South represents a global violence that disability scholars have begun to critique. Colonization, colonialism, and neo-colonial power in the global South have proven to be a devastating force for people living in these places. At the same time, the story of Aoga Fiamalamalama and Loto Taumafai show how lines of charity successfully leverage change while at the same time it allows the status quo to be maintained. In particular, I argue, colonial powers continue to exert control of resources, at the same time they deflect attention from this reality by promoting good works and benevolent practices.

Power and gendered dynamics are clearly a part of the story of the funding of these schools. It is worth probing the strategic approaches of organizers’ reliance on these funding sources to questions the economic and social values embedded in these structures. Specifically,
capitalist structures and the politics of location in building alliances and solidarities need to be accounted. Since most southern NGOs remain disempowered and unable to relate on equal terms to funders, the meaning of this relationship is that most still lack real autonomy or viability (Fowler, 1998). For example, the neoliberal capitalist approach of companies that search for trusted alliances while contracting poor people to participate as “employees” in NGOs financed projects is commonplace. The result of such practices will not enhance the ownership of development processes by local communities, which is often a prerequisite for empowerment and sustainability of benefits (Craig and Mayo, 1995).

The long-term vitality of the schools is also at the forefront of these concerns. In the time of global advocacy for inclusive education, international developmental policies, and the United Nations Convention for the Rights of Persons with Disability (UNCRPD), we can no longer ignore the disability community. However, the funding for these two schools was arbitrary and fostered no continuity for operation. Reliance on external funds also enabled the local government to take no responsibility for the education of students with disabilities. Coupled with the high turnover of staff working at such schools, ultimately these fundamental operating difficulties took a toll on how NGOs structurally operated and were able to succeed in their missions to create educational opportunities for students with disabilities.

Asking more nuanced questions about the logics of benevolence, charity, altruism, and its historical role in “helping” the disability community, especially in developing countries are critical conversations that reverberate throughout this study, but have wider implications. For example, how do corporate involvement in urban schools and the proliferation of charter schools in poor communities replicate many of these same dynamics? How do these corporate interests usurp government responsibility for the education of disenfranchised groups? If this history of
funding illustrates, an over-reliance on charity, good will, and benevolence can inadvertently hinder progress toward more consistent and long-term structures.

In the next chapter, I delve more fully into the early stages of the schools’ planning, as well as understanding the women organizers’ hopes and goals for the schools.
Chapter 5

Early stages and planning of the schools: “There was a need and we acted”

This chapter talked of the stories of the passionate and committed group of women, women with disabilities, and their allies who came together to organize schools for individuals with disabilities in Samoa. *Tautua* (service) is the Samoan concept of responsibilities individuals have to the collective aiga (family) and community. Thus, there is an expectation for community members to perform service that benefits the entire group. The idea of alofa (love) also applies to the important work of organizing schools for marginalized communities. The core founders of the Fiamalamalama and Loto Taumafai Schools often cited the concept of alofa as central to their sustained interest in organizing the schools. I contend that the influences of tautua (service), alofa (love), and faaaloalo (respect) greatly influenced the women founders’ understandings of their advocacy for disability, ma’i, and education.

This history remains a relatively unfamiliar history; not many know about Samoan women’s advocacy or understand how it helped to transform the community. It is important to uncover these histories and to acknowledge more fully the significant roles that indigenous women continue to have in our histories of education, policies, and culture. The women organizers’ explicit and implicit negotiations led them to advocate for the rights and inclusion of people with disabilities in educational institutions and empowered the broader disability community in Samoa. Aoga Fiamalamalama and Loto Taumafai Schools also demonstrated to the wider community that there was a need for inclusive educational and social policies. This
sentiment is captured in Lupe’s comment, “There was a need [for schools for students with disabilities]...and this is what we did!”

In this chapter, I focused on the early stages and the planning of the schools, as well as the women organizers’ reaction to the need for inclusive schools. I examined the founding members’ stories and their interest in the schools, focusing particularly on what alofa or love, tautua or service, and building coalitions meant to the founders as they carried out their advocacy. The remaining sections examined the organizing of the schools and the womens’ ongoing objectives of changing attitudes and aspirations. Lastly, I analyzed the wider meanings of organizing educational facilities and the influential roles played by parent advocates in this journey.

**Early Stages of Planning**

The “need” that Lupe points out (above) was indicative of the reason for the creation of the schools- to include people with intellectual or physical disabilities. As I discussed earlier, prior to the start of the Fiamalamalama and Loto Taumafai schools, students with disabilities did not attend formal government schools because they did not accept such students. Furthermore, the community held deeply ableist and moralist ideas of the type of student that was worth educating. Prior to the 1970s, students with disabilities lacked appropriate educational resources because formal education for disabled students “was always considered a low priority” (Lupe, personal communication, January 23, 2013). As Sharon, an administrator for IHC shared, “Some folks had the attitude that there is no need to educate these students with intellectual disabilities.” As these educational sentiments show, it is no wonder why disabled students were excluded in formal schools; this was the tone of educational access at the time.
Before the 1970s, extended family members cared for many people with disabilities, especially school age children, during school hours. The organizing of the Western Samoa Intellectual Handicapped Incorporated, in 1979, with the assistance of the Intellectually Handicapped Incorporated (IHC) in New Zealand, was really the beginning of special education in Samoa. This period signaled the status of people with disabilities belonged in school settings. Aoga Fiamalamalama formalized the schooling of people with intellectual disabilities within the existing education system. The coming together of passionate individuals to advocate for the education of disabled people in the 1970s was no coincidence; it overlapped with the larger political and policy shifts in the education system in Samoa and elsewhere.

Critical Coalitions

Coming together as a group was a difficult task. The coalitions of people who were committed to the education of all students and who directed the organizing of the schools were the focus of this inquiry. Initially, the preschool movement helped to prompt the organizing of Aoga Fiamalamalama and Loto Taumafai. What I mean by this is that educators in the preschool

13 In 1975, Special Education policies were also important in education history in the U.S., with the passage of Public Law 94-142. Congress passed Public Law 94-142 (Education of All Handicapped Children Act), now called as IDEA (Individuals with Disabilities Education Act). In order to receive federal funds, states must develop and implement policies that assure a free appropriate public education (FAPE) to all children with disabilities. The state plans must be consistent with the federal statute, Title 20 United States Code Section 1400 et.seq. (20 USC 1400)
movement were advocating for the inclusion students’ ages three to five as a part of the education system. The preschool organizers also collaborated with the disability advocates to support students with disabilities in the newly formed preschools. As a result, the preschool advocates and parents of disabled students banded together to push for inclusive schools.

Since the initial intent of Aoga Fiamalamalamala was to serve individuals with intellectual disabilities, the school founders, then, decided to organize another school (Loto Taumafai), primarily focused on the education of students with physical disabilities. According to Sina, “unfortunately our school [Fiamalamalamala] was not equipped for the many types of disabilities presented in these children--for example, hard of hearing, cerebral palsy with physical disabilities, in wheelchairs, blind or partially blind, epilepsy (ma’i oso tete), and brain damage from birth.” Therefore, the organizers got together again and brainstormed about the possibility of starting another NGO. Loto Taumafai was the result of this idea. By 1980, the preschool formally began with a student body of 20 (Afamasaga Telesia, personal communication, January 28, 2013). To clarify, when the preschool began it was not the intent to have an inclusive classroom; students with disabilities were not accepted into the classes until Afamasaga Telesia became a teacher of the preschool. Matter fact, she accepted students with disabilities because they wanted to come to school. Thereby, as Afamasaga Telesia pointed out, the “seeds of special needs” grew out of this practice and this is where the collaborations between the preschool and Aoga Fiamalamalamala started. More explicitly, the collaborations for starting Aoga Fiamalamalamala developed from the preschool movement.

Based on my interviews with the school organizers, many of them became involved because they had family members with disabilities or they were committed to the idea of educating people with disabilities. In addition, some of the women organizers advocated for the
schools because they identified as a disabled person, or was an ally of the disability community. For example, Fiasili, the former president of Loto Taumafai, was also a person with a physical disability, multiple sclerosis. Fiasili was deeply committed to starting an organization for disabled people because none existed. Moreover, her sister Fili related to me, “She was the driving force” of why Fili was involved with Loto Taumafai School. Then Lani came along, she was initially involved as a volunteer for Aoga Fiamalamalama’s fundraising events. Years later, Lani became a parent of a child with disabilities and continued to remain committed to the organization. As she puts it, “God had a plan for me and I am where I am supposed to be, I guess.” Certainly, organizers such as Sina and Faatonu were involved in the schools because they were parent advocates and they wanted also to change the landscape of the education system. During our conversations, Sina related, “As a parent, you want the best for your children; having a disabled son doesn’t change those beliefs. I want all children to be given the opportunity to be educated and become useful citizens.” (Personal communication, August 23, 2013) The other core founders and women organizers, Sisi and Lupe, were allies to the disability community. They felt that people with disabilities needed education and joined the movement to establish the schools. Neither of these two women had stakes in the disability community, but they shared the belief that educating students with disabilities was simply the right thing to do. Thus, the original cast of organizers came to school organizing and advocacy from different starting points, but they all shared a commitment to expanding educational opportunities for individuals with disabilities in Samoa.

**Agents of change**

As stated, the organizing of Aoga Fiamalamalama and Loto Taumafai Schools were due to the commitment of a small group of individuals. As a group, these women changed the
landscape of educating students in Samoa. The wider implication of their advocacy is that it raised awareness about the need for access to education for the disabled community and educated the broader Samoan society about alofa and change. The next section highlights each school organizer and her contribution to the schools. Regrettably, this is not a comprehensive list, as some of the founding members of the schools have moved away, declined to be a part of the project, or passed away. Sadly, as Sina narrated “most of our founding members from 1970-1980 were called to Heaven.” (Personal communication, August 1, 2012) Nevertheless, I felt privileged to learn from the extraordinary women who played a huge role in building these schools, as well as collaborating with international organizations to accomplish their goals.

I started with Afamasaga Telesia because almost everyone that I spoke with during my preliminary research trips mentioned her name as a key educator in Samoa. Coincidently, I also met her granddaughter, who is good friends with my niece. Through this connection, I was able to coordinate my schedule with Afamasaga Telesia, as she now lives in New Zealand. Afamasaga Telesia was an educator in Samoa, New Zealand, Fiji, and the broader Pacific. In Samoa, her reputation for “pioneering work” as Afamasaga Telesia calls it is legendary, especially in establishing preschools’ in villages. She also created the local early childhood education sector in Samoa, which eventually the Ministry of Education adopted. Afamasaga Telesia’s involvement with the preschool movement started in 1969, when she enrolled her two daughters in the preschool at the Protestant Church in the village of Apia. In her own words, this is how she became involved with the schools:

I had two girls and my husband was working as a lecturer at the Teacher’s College. When he leaves in the morning, I was faced with these two girls. I don't know what to do with them intellectually. I knew how to entertain them and all
that, but I was hungry for education myself. I thought how am I going to bring up these kids up when I don’t know how to bring them up in all spheres of themselves. That is when I saw a newspaper advertisement saying, ‘Kindergarten operating now at the Tamaligi Hall’. (Personal communication, January 28, 2013)

Not long after she enrolled her daughters in school, Afamasaga Telesia also became a teacher at the preschool. She was proud to share with me that this was the first time she got the opportunity to get a secondary education. Since her formal education ended at Form 2 [equivalent to eighth grade], she was excited to be educated with her daughters. Afamasaga Telesia had stopped going to school because her parents asked her to find a job, so she could help pay the school fees for her younger siblings. Her education stopped here and she was excited to return to school.

Having a preschool reinforced the idea that young children can learn and some community members supported the endeavor. Afamasaga Telesia jokingly said, “Everyone was at the preschool, the Prime Minister’s kids, Sina’s kids, church members’ kids, Lupe’s kids, government people, and probably your brothers and sister (referring to me).” Afamasaga Telesia’s comment was a sarcastic remark about “everyone”; meaning that not everyone supported early childhood education. The irony was that most of the government officials had their children in the preschool, but did not support the cause of creating more preschools in the villages. According to Afamasaga Telesia, the idea of special education also emerged when she was applying for financial aid grants while working for a government agency. She recalled, “The headquarters of the Early Childhood Education was in American Samoa [another island] and through my interactions with them, I learned about Special Education, or it was called handicap in those days.” (Personal communication, January 23, 2013) Afamasaga Telesia’s role
in supporting the organization of Aoga Fiamalamalama started in earnest with her accepting two students (Gele and Hone) with intellectual disabilities in her preschool classroom.

Sina and Afamasaga Telesia knew each other before they worked together as school organizers. Before Sina’s involvement in the schools, she was a labor and delivery nurse at the local hospital, a mother of five children, and a business owner. About how the women “found” each other, Sina shared, “We [women organizers] were all pretty good friends.” (Personal communication, August 23, 2013) Specifically, the women also had a lot in common with each other, for instance, because they were all living in the same village, their children attended the same schools, church, and extracurricular activities. Similarly, Sina had an older son attending the preschool and decided to ask if Gele, her second son could attend the school too. Reluctantly, Afamasaga Telesia agreed, and Gele showed up for school. Unbeknownst to Afamasaga Telesia, Sina told another friend Faatonu, parent with a disabled daughter, about Gele’s attendance in the preschool.

Faatonu was excited about the preschool and asked if she could also bring her daughter diagnosed with developmental disabilities to class. Faatonu was a parent of two daughters and a nurse at the local hospital. Here, the benefits of living on a small island came in handy, because “everyone knows everyone.” As Telesia conveyed, everyday parents were bringing their children with disabilities to her classroom. Word was spreading fast and frankly, as Afamasaga Telesia puts it, “We had to do something because we had a lot of students with disabilities in our classrooms and we were not ready for them.” Faatonu and her family’s role in the organizing of Fiamalamalama were especially important because her home was the original location of the school. At the time, the Protestant Church asked the preschool to move out of the hall. While the relocation of the preschool was underway, the students did not have a place to meet for class.
Faatonu volunteered to move the entire preschool (disabled and non-disabled students) to her backyard. It was not until the land in the village of Sogi was ready that the non-disabled students returned to Sogi, while the disabled students remained at Faatonu’s residence until Aoga Fiamalamalamama found a permanent location.

Thus, Gele and Hone were the first students who introduced Afamasaga Telesia to the unmet educational opportunities for students with disabilities. According to the women organizers, Afamasaga Telesia, Sina, and Faatonu were instrumental in getting the organization of Aoga Fiamalamalamama moving in the direction of a school. These women collaborated with the other educators, government officials, community and family members, church groups, and friends to gather support for the starting the preschools and Aoga Fiamalamalamama. Along the way, the women also connect with Lupe, a mother with six children, a teacher, and an artist.

Lupe was a great friend of all the women and so working together was an easy transition. Lupe did not have a disabled child. She was a grade school teacher at a local private school and an independent business owner. During our conversations, Lupe stated that she taught for about four years and then returned to her passion of doing art (wood carving, painting, and drawing). Lupe’s involvement with Aoga Fiamalamalamama started in 1980, when a friend invited her to a fundraising event. From then on, she got involved with the school and fully supported the concept of educating people with disabilities. Lupe shared her thoughts of why she thinks people were against educating people with disabilities. “I think it [negative attitudes about students with disabilities] was from a lack of education and people didn’t know or were [not] educated about them. So why would you pay to educate or give these kids an opportunity who were considered cursed or of no value.” (Personal communication, January 7, 2013) Lupe’s thoughts sum up much of the challenges that the women organizers navigated as they tried to gather community
support and government funding for the schools. Lupe was also involved in other NGOs on island as a consultant and mentor. She is very proud of her role as the former fundraising coordinator and treasure for Aoga Fiamalamalama.

Sisi was another founding member of Aoga Fiamalamalama School. Similar to Lupe’s involvement in the schools, she was not a parent of a disabled child. Sisi knew Afamasaga Telesia, Sina, and Lupe prior to the organizing of the schools. More importantly, Sisi also valued the undertaking of establishing a school for people with disabilities. She was very tickled about my request to interview her for the study. She said to me numerous times during our conversations, “You know this is just what we did; I didn’t think it was anything special.”

Likewise, many of the other women organizers were amused to be interviewed, as Lupe and Sina related, “no one has ever asked us about our work with the schools.” (Personal communication, January 7, 2013)

Interestingly, Lupe and Sisi had no personal investment in the schools, but motivated by the collective benefits to the community as educators. According to the other founding members, Sisi was instrumental in the “behind the scenes” interworkings of the school. For example, she worked with local attorneys to draft the school’s constitution, organized the Board meetings, served as a liaison to the international donors, and organized the accounting books and the fundraising events. During our conversation, Sisi was very humbled about her role as an organizer and attributed the school’s success to everyone else. She did share how proud she was that the school was still servicing students. Sisi continues to advise the Board and as well, as participates in the fundraising events and volunteer programs.

After coordinating everyone’s schedules for months, I was fortunate to be in Samoa when Sua, one of the founding teachers of Aoga Fiamalamalama was around. Like Afamasaga
Telesia, Sua also travels between Samoa and New Zealand. She has worked at Fiamalamalama since 1979, but in 2000, she retired. Sua’s sustained commitment to the school was also personal. Her grandson with an intellectual disability also attended the Aoga Fiamalamalama. She enjoyed working with the students and considered them her “fanau” (children). Sua’s longstanding leadership in the school led to the creation of behavioral management plans for new teachers. Sua was also proud of the workshops she conducted about behavioral management and discipline strategies for new staff members. She was particularly pleased about the lessons she implemented on using positive language when communicating with the students. As some of the women organizers shared with me, Sua was wonderful with the students, especially in the area of life-skills such using the restroom, organizing their homework, and communicating their needs.

To highlight her commitment to the students and the school, in 2012, Sua heard from colleagues that Fiamalamalama was looking for a teacher, so she returned to Fiamalamalama to work for two days until a teacher was hired (Personal communication, January 10, 2013).

As previously mentioned, Lani was another parent with a daughter who attended Fiamalamalama and Loto Taumafai. Before having her daughter, Lani was already involved with fundraising efforts for the school. According to Lani, “I joined as a member in 1979, with my friend Pika. Not knowing that I will have a child with a disability; I used to go to the fashion show fundraisers and usually participated.” (Personal communication, December 28, 2012) Lani became involved in the school in the mid-1980s when her daughter was a student at Fiamalamalama. Lani was instrumental in raising awareness about people with disabilities, especially women with disabilities in the community. Lani often met with local funders, conducted education workshops with her daughter, and worked with women’s religious committees and groups to support the disability community. Lani, like the other parents,
continued to advocate for the rights of people with disabilities in Samoa and abroad. As an educator, Lani continues to speak locally and internationally about disability rights and challenges faced by the disability community in Samoa. She is a school Board member and supporter of Fiamalamalama even though her daughter is no longer a student.

Fili was another founding member for Loto Taumafai. As mentioned, she got involved with the school because of her sister Fiasili. While also working with Loto Taumafai, Fili was an employee for the Tourism Authority and also a local business owner. Fili does not have a disabled child, but that did not limit her involvement with the school. My exchange with Fili also demonstrated the commitment that family members had to the disability community. As Fili shared, “My siblings did not get involved in the school’s inner workings or Board [members], but they contributed financially to a lot of events and needs of the school--usually anything from using a truck to moving fundraising supplies to buying tickets to the fundraisers.” Some family members, like Fili, continue to support the school(s) as a way to honoring the legacy of her sister. Fili remembered Fiasili as, “A wonderful role-model and she kept her hand in there [running the school] and the kids love[d] her.” (Personal communication, February 5, 2013) Today, Fili continues to work with the school as a patron and honorary Board member.

Additionally, Dr. Viopapa was a founding member of Aoga Fiamalamalama. She became involved in the schools as affiliate medical personnel. As some of the women organizers related to me that Dr. Viopapa was a critical member of their team because she worked with the international medical staff that often came to Samoa. She took on the responsibility of engaging medical professionals and always advocated for the school. She also had the expertise to apply for grants that often went to the local NGOs. At the time, she was a pediatrician, working in a private practice. When the women organizers approached her to help them, she happily agreed
to assist with medical advice aspect. According to Dr. Viopapa, cerebral palsy is the most common disability in Samoa. However, she suspected that delivery and birthing procedures might contribute to these factors. She also shared an interesting insight about the Samoan community and their views of disability. She related:

Samoan people do not deliberately mistreat people with disabilities, the problem is that they are overwhelmed and the families often don’t know what to do. [She goes on to explain], people need support and resources about disability, as well as ongoing family supports. (Personal communication, February 8, 2013)

In other words, she believed that negative attitudes about disability or exclusion did not necessarily mean that people were intentionally mean spirited. Instead, she flagged the local government’s responsibility to the community to offer services for mental health and special needs students. She believed that the government often takes the opinion that, “this was a private issue] and civil society issue.” (Personal communication, February 8, 2013)

More importantly, Dr. Viopapa continues to be an advocate today for the disability community. She is a long time social activist and continues to work in the Civil Society Support Programs, an organization that helps NGOs apply for funding. She is particularly active in the organizations that are involved with women and gender rights, disability services, education and health programs. Lastly, Dr. Viopapa also agrees with her colleagues that changing attitudes in Samoa is an ongoing challenge for people with disabilities.

In summary, the eight women highlighted in this section were core founders and organizers of both schools. Several men who supported this founding group were attorneys and spouses of the women organizers, who worked on the legal and medical issues for the schools. Believing in change and access were some of the beliefs that brought all these individuals
together. Notably, none of the core founders monetary payment for their advocacy. In fact, they used their social, financial, and political capital and privileges to contribute to the schools’ development.

A Labor of Love

The theme of alofa (love) often featured in the stories told by women organizers. Alofa was a metaphor used regularly by the women organizers to articulate the motivations behind their advocacy. Alofa was as a tool to remove the barriers of ableist and normative structures. Understood in everyday Samoan language, alofa used as the noun, love, but also used as a verb for showing love; the women often cited the phrase “E se alofa ma’i i’a au” or “Don’t you love me, [if you do please help]” to each other during their organizing efforts. The phrase “se alofa ma’i” also has the interpretation of a pleading/request for help. As Sisi, clarified, “We [she and her spouse] donate a lot of things for IHC and for the fundraising…my guys run the bar and the trucks to help move things; we bought the sliding doors for the classrooms; buy the ice cream and bongo [chips], and wrap the gifts for the students. It is tiring.” Sisi’s example of what she and her family do for Aoga Fiamalalama was representative of the kinds of tasks that other organizers did for the schools. Therefore, alofa for the women organizers has been a term used to motivate each other to keep working for the school. Sisi used Sina as an example of why she keeps working with IHC. She said, “I would not have carried on if it wasn’t for Sina. She is really awesome, one of the best I’ve come across, and she is a hard worker. She [Sina] says, ‘E se alofa mai ia a’u’ [or Please don’t you love me?] and I have a lot of time for her” (Sisi, personal communication, February 7, 2013). Such statements about alofa were encouraging to the women and provided a way for them to be accountable to each other in their tautau or service. Alofa became an obligation tool to keep each other committed.
Grassroots organizing of schools

The women organizers met their goals in large part because they had social and economic capital to draw upon. As mentioned earlier, many of the women were business owners—with both financial means and flexible work schedules. Not only did the organizers use their privilege to organize the schools, they used their social, political, and cultural capital to change patriarchal and ableist views about their roles as mothers and homemakers. By using their organizing and leadership skills, the women organizers established schools despite the dominant ideologies of exclusion in the community. Moreover, the women organizers used their networks to seek support for the schools. One of the first steps that the women organizers accomplished was finding allies and community members who supported their cause. As Sina and Lupe implied, “We talked to a lot of people about the school. We talked to people in the government, the schools, the churches, and anyone that listens to us.” Despite the preliminary efforts by the women organizers to elicit help from those in their communities, they realized that they needed something more concrete to formalize their plans. Faatonu, Sina, and Afamasaga Telesia gathered everyone who was interested in their cause of starting a school and came up with a strategy. According to Sina, “We called a public meeting at the ‘Maota Ole Alofa’ or ‘Place of Love’ in Apia, located in the building owned by the Tina o Samoa or the Committee of Women in Upolu and Savai’i [islands].” The group wrote a proposal and submitted it to several government agencies for funding and support. At the same time, Afamasaga Telesia was already applying for grants from international agencies. Unfortunately, none of the local funding came through, so the women shifted their focus and applied for international grants. Luckily, the IHC (Intellectual Handicapped Centre) in New Zealand responded positively to the women’s request to a start a school for people with disabilities. As Afamasaga Telesia related, “I wrote to Dr.
Munro, the director of IHC in New Zealand and he answered that he is going to come [to Samoa to potentially open an affiliate organization]. He came over and started talking to Dr. Viopapa and they started an interest in Samoa.”

One of the pressing challenges for the school involved finding a physical location. As Sina pointed out, “We didn’t have anything [location for the school] at the time, so we started with organizing a Centre first and then eventually moved to opening a school.” (Personal communication, February 7, 2013) The Centre that Sina mentioned was the starting point of the school. According to the women organizers, the location of the Centre was at the preschool and occasionally at one of the women’s workspace or home. The Centre included the seeds of the later infrastructure for the school--for instance, an executive office, named Board members, and eventually staff members. However, the following year, Faatonu and Sina suggested that the Centre move to a building where they would not have to pay rent, while they searched for land to establish the school. According to Afamasaga Telesia, it was at this point that the preschool and IHC became separate and independent organizations.

Parent advocacy on behalf of students with disabilities is not a new phenomenon and many (but not all) of the organizers had children with disabilities or some connection to disability in their family. Historically, parents have been influential in changing the exclusive educational policies and culture in school procedures and practices. Parents have often been the force of change behind the inclusion of students with disabilities in classes, policies, and asserting the rights of their children to participate in schools (Ballard, 1999). In Samoa, parent advocacy on behalf of children with disabilities led to reforms in the school system. Arguably, the school system would not have changed their procedures and practices without parent and community-member demands.
Gendered roles

The women’s cultural capital, organizing strategies, and advocacy skills situated them as a special group of social actors. Terms such as mother’s work used to describe social movements of women that are not necessarily valued or recognized by society. More broadly, the term “mother” loosely defined in numerous ways depending on the context. My use of this term extends the meaning to include women who are not mothers to either biological or adopted children, but include women who are mother figures or who care for individuals in the communities. These extensions in the definition of mothering disrupted the heteronormativity views of women as bearers and transmitters of culture and knowledge and relegated to the domestic realm. In the process of connecting women with practices of domestic and cultural labor, it objectified women and stripped them of their agency. The shift in understanding a broader definition of mother’s work by women who do not identify as “just” mothers is also essential to this conversation. More importantly, the participants seldom acknowledge the gendered roles associated with the women’s labor in organizing the schools publicly. While most of the key leadership roles in the schools are in the hands of and carried out by the women, in my interviews some of the women deferred to the men in the group, who were attorneys and physicians, as the “leaders” of their group. However, many of the women organizers had agency within their capacity to organize the schools, gendered dichotomies of paid work/house and mother work divisions seemed to serve as a mask to the political work performed by the women. I was especially curious as to why the women would uphold heteropatriarchy (Arvin, Tuck, & Morrill, 2013), which normalizes the dominance of men over the subordination of women, when clearly from the interviews and the school documents, the women’s labor was the driving forces behind the schools’ creation. This point made me think about contradictory approaches to
womens’ advocacy as one that resists oppressive structures, while simultaneously enforcing Christian values of women as “subservient” wives.

In considering mother’s work, I think the stories shared by the women pushed the limits of the definition of heteronormativity. Actually, some of the “mothers” in the group were defined as outsiders in their communities, because they did not fit ableist views of a caregiver, parent, and woman. Lisa, for instance, a woman with a condition called “brittle bones” spoke about her experiences as a student, mother of two children, wife, and teacher at Loto Taumafai. She related that some in the community doubted her ability to take on all these roles that most women in the community occupied. Lisa commends her parents for molding her into a strong person. She recalled, “My mother always made us go to school. She constantly encouraged my younger sister (who has the same condition) to attend school, no matter how tired and in pain we were. [She would say] ‘Go to school and learn something’; Lisa fondly remembered her mother as someone who pushed her to continue going to school, “She never allowed my disability to be an excuse to be absent from society or school.” Because of her mother’s advice and guidance, Lisa credits her for her career choice as a disability advocate. After graduating with a bachelor’s degree in Applied Sciences, Lisa returned to Loto Taumafai and worked as an administrator and teacher. Currently, Lisa is a patron of the school and continues to collaborate with Loto Taumafai and another disability advocacy organization (NOLA) primarily staffed by people with disabilities.

Similarly, Fiasili was a mother figure to numerous students. Though she was not a biological “mother” in the traditional sense of the word, she worked with students as the president of Loto Taumafai. Fili, her sister, later took on a leadership role at Loto Taumafai. She described her sister Fiasili as, “A woman with a disability who was not afraid to advocate for
what she believed; she believed that all children should have the opportunity to be educated in schools.” (Personal communication, February 6, 2015) Fiasili’s vision for the education of people with disabilities also encouraged others in her family and close circle of friends to be excited about Loto Taumafai. Their work as mothers and mother figures were influential in the school’s success and central to the identity of the women in this study. Women played an integral part in establishing the schools while also carrying out most of the leadership roles in the schools. Their efforts speak to the commitment that the school organizers took on, regardless of monetary gain or status.

Another aspect of this “labor of love” focused on community-based activities. Historically, gendered work for women often involved unpaid work in churches, schools, childcare programs, hospitals, and recreation centers. This aspect of their work mentioned in a conversation I had with Pua: a former educator at Malua and Wesley Seminary Colleges (started teaching in the mid-1960s), an advocate for the Early Childhood Education and inclusive education, and a mother of four children. Pua’s spouse was a minister in the Methodist Church and was a principal at the seminary college at one point. Pua’s involvement with the church began when she started teaching at the theological colleges. Based on the women organizers’ recommendation, I met with Pua to talk about her role as an educator in the seminary colleges and as an early childhood education supporter. Pua’s experience with disability was more on the personal side as an educator. She remembered a student name Tito, with a physical disability that was often late to school. Tito ended up living with her family while he was attending Malua Seminary School. She recalled, “He live[d] too far away from the school and he was a boy with a crippled leg. He was one of the twenty students living with us.” Pua shared that another person living with her family was, “a fellow who had polio or got polio from a bad vaccine. He lived
with us and helped us in various ways, but he didn't go to school.” Another woman, “who had one eye that was not right; she also lived with us, like Tito. So our family was inclusive as well.” As Pua stated:

We were kind of an inclusive family and [were living] inclusive education from the very beginning. It wasn’t a term yet [inclusive education] maybe in 2000. I was not aware of the term until I was on the Board of SENES [an inclusive education NGO that started in 2000]. (Personal communication, February 13, 2013)

My conversations with Pua illustrated the everyday side of disability that the women in the study wanted to change. Similar to Pua’s experiences, some of the women organizers not only advocated for people with disabilities in schools, but also lived with disabled people. I suspect that these experiences of understanding stigma, lack of access, and shame attached to people with disabilities drove their advocacy. Although Pua was not directly involved in the organizing of Aoga Fiamalamalama and Loto Taumafai, her involvement as an educator and supporter of the disability community speaks to her contributions in the Samoan religious community. What was most touching about my conversation with Pua was when she showed me the graveside of the young man with polio that lived with her family. He was buried in their family compound [homestead] because “he was family.” Sadly, when I asked about his biological family, Pua related that he was pretty much an “outcast” and that is why he lived with her family.

Intriguingly, Pua’s comments also reflect some of the stigmatizing discourses of the time (1960-1980s) about the status of people with disabilities or differences in Samoa. Pua believed that by having people with disabilities live with her family, they inadvertently helped to educate her biological children about accepting peoples’ differences—a goal that the women organizers also
strove to accomplish. Here she aligns her work with another meaning of alofa, which can also mean, “giving them [particularly the most unfortunate] a bridge to help them succeed.”

Understanding the logic and motivation behind the women’s advocacy and organizing efforts helped to explain their roles in changing dominant views. The women’s organizing strategies were partially under the control of and influenced by public policy, which in turn continued to reinforce inequities. However, the women were also conscious of the ways that reform policies to change negative attitudes and practices. Another important factor that drove the women’s advocacy and labor was that many of them were from middle and upper socio-economic groups. This meant that some of the women had the financial resources to carry out their work. This was not a common aspect of grassroots organizers. As most grassroots organizing start with people often exploited and oppressed (Biklen, 1983; Ray, 1999; and Roces & Edwards, 2010), this study is different in that the women organizers used their power and networks to change oppressive systems. Most of the women organizers were also educated outside of Samoa. Therefore, the women’s social and economic privileges worked in their favor (Jolly, 2001; Dyrness, 2011; and Kafer, 2013). Finally, cultural and gendered notions of love and care motivated the organizers but in some ways, it also seemed like a challenge that the women dared to take on. Although, these changes also benefitted the women organizers, the implications of the women’s organizing approaches were that many families on island were also able to educate their children with disabilities. As the disability advocate Roache (2008) reminded us, disability issues are never just about people with disabilities, they are about everyone. The next section of this chapter examined education as an important site for this kind of social, political, and cultural transformation.
Education Advocates Not Activists

Many of the women organizers viewed education as a space that had the potential to foster change in the wider community’s attitudes about people with disabilities. Lani shared with me that when her daughter Sasha first started school, it broke her heart when she asked why she could not go to the same school as her siblings. Similar to Sina’s experience with her son Gele, Lani also made it a personal goal to change the stigmatizing attitudes that people had about disabled people. Lani shared with me that, ironically, Sasha loved going to school even though segregated from her siblings. She loved her friends and especially getting lunch money from her parents. For these reasons and more, Lani used access to school as a platform to raise awareness about the need to change attitudes regarding people with disabilities. As Lani commented, “Having Sasha in your school is a lesson in itself. And we have experienced some tough times with her in school.” According to Lani, Sasha has always self-advocated for herself and her friends. As a protective mother Lani’s concern for Sasha in school was about the cruel comments that other students and adults might make toward her. “You know, Sasha is a force to be reckon with, she is strong-willed, funny, smart, and sassy. But, it is still hurtful when someone calls your kid mean names.” Lani further explained, “although Sasha is articulate about her needs, and I have heard her tell people ufa [fuck you], aikae [eat shit], and go to bloody hell when she is angry with you. I am still protective of her…even more with her than my other children.” (Personal communication, December 28, 2012) Locating school as the setting for the women’s activism was important because education has been an un-inviting space for students with disabilities. The stories participants told about children wanting to go to school motivated their efforts, but the difficult task was really about negotiating creative ways to make the schools
more inviting for students with disabilities. Thus, schools, as educational institutions, must be interrogated as spaces of injustices and inequitable access and benefit.
Colonial Remnants. Schools have always been spaces of colonization and
decolonization--of oppression and assimilation, but also resistance. As Tina, an administrator for
the Department of Education in the 1970s, said, “We were out to get independence, *le maua ai le
mau a pule* [sovereignty], education was the be all end all of everything.” (Personal
communication, February 5, 2015) Tina further explained that education meant that students
graduating from high school could go on to college and then return home to teach our children.
She stated that Samoa College [local high school] in the 1960s was geared toward training
people who “would make up the government. [They] trained teachers, nurses, doctors, and
lawyers, and so on.” (Personal communication, February 5, 2013) According to Tina, even after
Samoa became independent, the public schools curriculum shifted depending on the country’s
need. The curriculum also reflected the period and political context, “because time [was]
changing and the elitist system, which made the government possible, was still there.” (Personal
communication, February 5, 2013) Later on in our conversation, Tina added that the changes in
the education system aimed to dismantle slowly colonial structures. She recalled that after
gaining independence, “all the districts [villages] broke away and had their own primary and
secondary schools.” Tina felt that the motivation behind decentralizing the school system came
from the community’s investment in sending more students to Teachers Training College. As a
result, the understaffed schools were able to hire more teachers, while making efforts to
encourage more teachers to stay in the profession.

The shortage of trained teachers was in large part a result of independence. When the
New Zealand administration left, so did some teachers. The government schools eventually
organized smaller divisions and the village districts and school committees took on the
responsibility of managing the schools, as opposed to depending on the Department of
Education. As Tina speculated, people in the villages were motivated by the changes (independence) in the country and this prompted them to be more active in the organizing of local schools. Mobility and independent decisions were some of the reasons why reforming the education was also enticing to the districts and parents. With colonial governance, the Samoans were not in a position of leadership to change educational policies and structures. Therefore, gaining independence prompted the changes within education, including the ability to establish new curriculum areas (such as vocational programs), and the ability to fund new secondary campuses (such as Vaipouli and Avele Colleges, local high schools), which were located in the rural areas of the island.

The macro structures of decolonization that were taking place across the country at the time were also happening at the grassroots level. On the micro-level, disabled students and preschoolers shaped the reform of educational policies. The 1970s and 1980s were a vital time for changes to the education system, as it disrupted discourses of ableism and normativity in colonial structures. The women organizers were strategic in their timing and used this transitional period to push for changes in educational access and policies.

The Advocates. One of the reoccuring themes that emerged in the interviews was that the women organizers did not consider themselves as activists. To address the identity politics embedded in these conversations, I focused here on the struggle to claim or disavow the label “activist” in their work. For the most part, many of the women interviewed in this study did not self-identify as “activists” with regard to their roles in organizing the schools. Their resistance to identify as activists revealed a disconnection between “doing activism” and “being an activist.” In turn, these negotiations challenged me to consider the ways that “collective identity” serves as a means to stimulate social action (Bobel, 2007). This point is particularly important within
social movements because the alignment of personal and collective identities is not necessarily fundamental for movement participation. As Bobel argued, “one can ‘do activism’ without ‘being activist,’ and this discrepancy suggests a more complicated account of identity at the center of the study of social movements” (p. 149).

When I asked the women organizers to explain what term best described their efforts, they said, “That is just what we did.” For example, Sisi questioned whether she really “belonged” in the category of activist, because she [and the women organizers] didn’t really “do anything special.” The women’s questioning of whether they really qualified for the category of activist was striking to me and presented a more complicated account of identity in advocacy work and social movements; this casual and unassuming understanding of their tautua (service) to the community fascinated me because it implied a sense of responsibility and ownership in social welfare matters. It also made me consider Samoan values of obligation that rarely verbalized but often carried out within the community. The assumption is that Samoan people “know” what they need to do without being told; certainly a lesson that I also grew up with in my family, which is sometimes hard to explain. For example, Pua shared with me a similar story when she married into her spouse’s family. She explained, as a daughter-in-law, “you are expected to know everything and do everything exactly how they do it in Samoa, and there is no leniency if you can’t do that.” I think this message of “knowing” your role and responsibility in the hierarchy of social order reflects both gendered and normative protocols in Samoan culture. It is also indicative of an ingrained value and belief system passed on from generation to generation. The disadvantage of presumed values of knowing is that they are difficult to critique because it is so normal in the community; to
differ from the norms, sometimes, can take on the explanation of an individual trying to be a “rebel” as earlier affirmed by the women organizers.

Perhaps further explanations of such understandings align with Samoan ways of self, being, thinking, and becoming. The Head of State, His Highness Tui Atua Tupua Tamasese Ta’isi Efi, refers to this as “the Samoan indigenous reference” (Suaali’i-Sauni, Tuagalu, Kirifi-Alai, & Fuamatu, 2009). Notably, Tui Atua was an early supporter of Aoga Fiamalamalama School. In the mid-1970s, he was the Prime Minister of Samoa, and the women organizers often went to his cabinet to ask for financial support. According to Tui Atua, “It was Sina and the womens’ hard work and persistence that created the school” (Tui Atua, personal communication, January 9, 2013). Lupe shared that one of their first grants for Aoga Fiamalamalama was for $10,000 tala or dollars; these monies came from the local government during the time Tui Atua was in office. Humbly, Tui Atua related that his ongoing work within the mental health and disability realm also had personal significance for him: “I promoted it very strongly because people did not understand the importance of mental health” (Tui Atua, personal communication, January 9, 2013). Today, Tui Atua is an outspoken advocate for mental health services in Samoa New Zealand, and Europe.

Thus, in terms of how the women defined their work, they operated within a specific set of values and beliefs that reflected the larger cultural context. The women adopted a self-definition of the work they did as culturally grounded. When I asked Lupe to define her role in the schools’ organizing, she explained that if given the choice between the words activist and advocate, she would identify as an advocate. Activist to her denoted an image of women in the 70s protesting and picketing, and that was not her style. They approached the organizing of the school as a collective effort, which would benefit many people in the community. She also
reminded me that, acting like a “rebel” in Samoa [alluding to protesting] would “only turn off people or get them in trouble with our families.” Lupe refers to the family shame and embarrassment that their families might experience because of their public display of discontentment. She explained, they would not “go there”.

Complicated factors of power relations and privilege intertwined in these conversations. Their narratives taught me to respect participants’ agency in defining themselves rather than imposing my own biases. I have also had to learn to acknowledge my limitations as a researcher. The women taught me that although I viewed activism favorably, their peers frowned upon the use of the word activism and “activist” because it portrayed them as “radicals”. They did not want to disrupt cultural values, but did want to find ways to advocate for inclusive schools as an important and needed change. Our negotiation of these terms was a great example of the ways that struggles around words, language, and labels driven by embedded ideological and philosophical values. A difference in how the women defined their work against ableist structures might have the definition as one example of the fluidity in their identities as agents of change. For the organizers who were also mothers, advocacy and activism were a major part of their experiences of mothering a disabled child. In fact, advocacy on behalf of their child(ren) often remained an unrecognized, yet valued aspect of their parenting role. In fact, many of the women laughed and shrugged off any personal connection to activism, but as Fili also admitted, “It has made me carefully think about our roles in the school.” In the next section of the chapter, I discuss the decisions that went into the organizing the schools.

The Making of the Schools

Aoga Fiamalamalama and Loto Taumafai
The organizing of Fiamalamalama School was a collaborative and collective enterprise. By 1979, the IHC Samoa, Western Samoa branch was established and the Aoga Fiamalamalama School opened its doors soon after. Parents of students with disabilities and their allies were excited about the opening of the school. They also understood the difficulties surrounding the physical and fiscal maintenance of the school. This new concept of including individuals with disabilities (often referred to by the public as “kids” regardless of their age) in school was novel. Moreover, given the prevailing sentiments at the time, creating a school for disabled students seemed by many as unimportant. Such attitudes continued reinforcement by ableist myths that attributed disability to a personal misdeed or curse. Nonetheless, the women organizers plugged ahead with their plans.

The Loto Taumafai Society was founded in September of 1980 (Keil, 1981). According to Sina, the motivation behind creating both the Loto Taumafai School and Fiamalamalama stemmed from the dire need for more educational services for the disability community. After Aoga Fiamalamalama opened, many students with various physical disabilities started attending. Unfortunately, the limited space at Fiamalamalama necessitated creating a second school. The women organizers knew that further separating students based on the nature of their disabilities was not ideal, but it was the best option at the time.

The students were divided into age-appropriate classrooms (e.g., having a classroom designated for students ages five to seven and another classroom for the older students). Some students attended both formal and “special” schools on a part-time basis. However, some preferred to stay at Loto Taumafai School all day. Initially, Aoga Fiamalamalama and Loto Taumafai collaborated in referring students to each other. However, as the women organizers made clear in their interviews, this was not always or consistently the case. Tensions between
the two organizations led to frequent transitions in leadership and competition for meager funding from local agencies.

Early on, the founding members of Loto Taumafai School shared a few of the same organizers as Aoga Fiamalamalama. For instance, Sina, Lupe, Fili, and Sisi were advocates for both schools over the years. Several years after Loto Taumafai started the culture of NGOs for disability changed. According to Fili, the change geared towards streamlining the NGOs into “an umbrella organization for all the societies” (Personal communication, February 5, 2013). Loto Taumafai was now the umbrella organization for all disability groups, but this plan did not come to fruition. As Fili revealed, “For some unknown reason it did not work out that way.” (Personal communication, February 5, 2013) The reason cited by most organizers was that each school and organization wanted to remain independent. When the initial agenda to link all the disability organizations in Samoa failed, the name of the organization was changed from Loto Taumafai National Organization, to Loto Taumafai Educational Center and, finally, to Loto Taumafai School (Fili, personal communication, February 3, 2013).

Despite many creative strategies used to keep the schools running, high staff turnover was an ongoing and upsetting challenge that the founders continued to deal with. The impact of these disruptions in school services and programs often led to substandard education for the students. When I asked the women why they were not as “involved” in the operations of the school, many stated that they implicitly trusted the leadership team and could only do so much at the time. Indeed, many felt that they should step back from their responsibilities and allow the hired staff to run the school. As succinctly captured in Fili’s words, “It’s time to pass the torch to the next generation.” (Personal communication, February 5, 2013) She emphasized her elderly age and strongly felt that the younger generation ought to take over the reigns.
Curriculum. At the start of the school, the curriculum at Aoga Fiamalamalama mostly resembled what some would consider home economics and vocational education. According to Fili, the students learned how to sew and do handicrafts. Each week the students also studied a project. For example, the students were learning about “People who help us.” Another week the topic was on Hospitals and the Police Department. The lessons for the week often consisted of activities such as drawing, writing, free play, songs, rhymes, stories, and discussions. The students went on field trips to the local hospital and police station. According to Sua, four of the students were deaf, so sign language was also a big part of the student’s curriculum. Coincidently, many of the students who were not deaf also learned sign language from the teachers and each other.

The school’s curriculum also reflected the government school curriculum in math, science, language arts, and history. Fiamalamalama also taught Samoan language and the curriculum used both Samoan and English. However, the school experienced tension surrounding the curriculum. Fili shared a time when a new teacher took over (about 2-3 years after the school started) at Fiamalamalama: “She [the teacher] was not interested in teaching the mentally handicapped; she was interested in teaching at a normal school; so whatever didn’t suit her, she threw out [referring to the sewing machines and art equipment].” (Personal communication, February 5, 2013) Fili’s comment is reflective of the expectations that staff members projected onto the students, which was reflected in what they saw was essential curriculum. In other words, some viewed the students as capable of a more academic curricular focus, whereas others viewed the students as needing a more functional or life-skills curriculum. Staff also came to these positions with different expectations and motivations. Each of these factors influenced the stability of the school and its educational offerings. Many teachers did not
remain in these positions for long because they had other aspirations. High staff turnover added to the lack of continuity in curriculum and instruction, which then negatively affected student progress.

The curriculum at Loto Taumafai was similar to that of Fiamalamalama. Both schools tried to emulate government school curriculum, however, depending on the teaching staff, the lessons varied. As Lupe affirmed, many teachers and administrators came and went throughout the years. At the opening of the school, Loto Taumafai had older students who were most likely in upper elementary and middle school. More likely, the students had gaps in their educational backgrounds due to their exclusion from schools. A challenge that both schools faced, which also added to the curriculum difficulties, was the age range of the students. According to Sua, students at both school stretched from ages 5-19. The age range also made it harder for the teachers to gear their lesson plans to specific age groups, as some of the students combined in one or two classrooms. Sua also shared that despite the age range, many of the students were performing at different (often at lower) grade levels. Therefore, training the teachers to adjust or differentiate their instructional lessons was not an easy request. Sua shared that even as a certified teacher, she continued to take professional development courses because she still felt “behind [inadequate] in my teaching of the students.”

**Founding Students.** At Aoga Fiamalamalama, four founding students started when the school first opened in 1979. By 1980, the school had grown to 16 students, consisting of eleven boys and five girls. The students’ ages ranged from 5 to 18. Among the first students who attended two students diagnosed with Down syndrome, three were deaf, and four others who had
labels associated with intellectual disabilities$^{14}$ or developmental delay, some of whom also had limited speech (Vulger, 1980, p. 3). According to the school attendance records, about nine students attended school daily. The school was open on Monday to Wednesday and Friday; with school hours were from 8:30 am to 1:30 pm. The students did not attend school on Thursday because it was professional development day for the staff. According to school memo, “Each Thursday the Teachers prepare their programme for the next week. On alternate Thursdays Teachers also make home visits to parents” (Vulger, 1980, p. 1). Families dropped off most of the students at school, but one student took the public bus to school.

Before the school relocated to the village of Alafua, the school held classes in the village of Leufisa in the backyard of the Faletoese family. The above report stated that, “The school building is a “fale” situated at the back of Mr. & Mrs. Faletoese’s residence and has been very kindly made available by them for the use of the Disabled School. Toilet facilities and water are also available at the home of Mr. & Mrs. Faletoese” (Vulger, 1980, p. 1). The school building comprised of two rooms, one room was about 30 feet by 15 feet, and this room was the main classroom space. The other room was for storage. The classroom had “adequate cupboards and a black board.” The students sat on Samoan mats (woven mats made of pandanus plants) at low tables, which did not require chairs. At the time, there were no special seating requests because all the students were mobile. The school operated based on two terms: February 9 to May 15 for 14 weeks and from June 8 to September 4 for 13 weeks. The school fees were “$5 per term” and

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$^{14}$ The term “retardation” was used in the actual report; however, I have replaced this term with “intellectual disabilities” because it is a current and preferred terminology that is not derogatory.
the students had three weeks of school holidays (MacKenzie, 1981, p. 2). In addition to the modest tuition, the staff asked parents and/or relatives of each student to donate one day of volunteer services to the school. At the time, the tuition costs were similar to the government (or public) school fees. For the average family, this was expensive and reflective of the population of students not in school, and there were no compulsory education policies until the 1990s. In addition, students from the Marist Brothers, a local all-boys Catholic high school, also volunteered at the school. A newsletter from the time reported:

A group of five boys from Form 2 visit our school 11AM-12PM every Tuesday and Thursday. These visits are of great help to both teachers and pupils. One aspect which is more noticeable during these classroom programmes with these students is that the child’s language patterns are most rapidly improved by quantities of one-to-one conversation with a normal teenager. (MacKenzie, 1981, p. 5)

Such practices of having non-disabled peers at Fiamalamalama, I would argue, laid the groundwork for inclusion—making the case for disabled students to have social interactions with typically developing peers furthermore, for those peers to get to know their peers with disabilities. Moreover, these peer interactions and exchanges seemed to benefit all students.

**Loto Taumafai Opens its Doors**

Loto Taumafai School had a somewhat very different beginning from Aoga Fiamalamalama. First, the school started after Aoga Fiamalamalama in the 1980s. Initially, Loto Taumafai was a “Centre” and enrolled more secondary students who attended the school part-time. According to the Lupe, she was aware of six students who attended the school regularly because these students also went to Aoga Fiamalamalama. The number of founding
students are bit blurry at Loto Taumafai because most of the students were also considered “members”, which meant that they “come and go” while also attending government schools. In the early 1980s, leadership in the school changed and the school enrolled more deaf students along with students with physical disabilities. According to Fili, there were about 28 students at this time and over half of them were 18 years of age or older. For the older students, the curriculum focused on vocational skills, for example, woodcarving, carpentry, art, and home economics. Many of the adult students also worked in local businesses. For the younger students, the curriculum often mirrored that of government schools. However, the curriculum of both schools was inconsistent because of the high turnover of the teaching staff and administrators.

**Teachers and Staff**

The founding teachers at Loto Taumafai came from New Zealand. According to the women organizers, most of them stayed on island for two to three years. Local teachers also worked as staff, and the plan was to train these teachers to take over the teaching responsibilities, eventually. For Aoga Fiamalamalama, the three head teachers were Mrs. Sierra Vili, Head teacher, Mrs. Suafalaoa Mann, Assistant Head teacher, and Mrs. Tusifolau Toma, Teacher. The teachers used many donated materials from various organizations. For example, they had a new Polaroid camera, tape recorder, jigsaw puzzles, blocks, wood trucks, dolls, puppets, posting box, soft toys, a mosaic board, a matching set, and colorless wooden developmental equipment (Sua, Personal communication

Loto Taumafai School’s first principal was Suafole I’iga and the organization’s first president was Moira Walker followed by Fiasili Keil (Fili, personal communication, February 5, 2013). According to Fili and Sina, the founding principal and teachers were volunteers from
New Zealand. The volunteers “would come for two to three terms or several years” and the idea was that they would train the local school staff to take over when they left. Unfortunately, these staffs’ turnovers lead to an inconsistent mode of operation for Loto Taumafai, which left the school in messy situations. In an attempt to work together with Aoga Fiamalamalama, the decision was made to appoint Sina as a representative or liaison from Fiamalamalama, even though she was one of the founding members of the school. The goal was to share resources between the schools and resolve the challenge of finding and keeping qualified staff members. Unfortunately, both schools continued to have these difficulties over the years.

**Changing Attitudes and Aspirations**

Creating the schools and advocating for the rights of people with disabilities was not a simple process. The schools laid the groundwork for increased educational opportunities and inclusion. Along the way, the women collaborated with organizations (such as the faletuas or pastor’s wives), government officials, and village elders. Despite efforts to educate and raise awareness, negative attitudes toward people with disabilities remained one of the hardest tasks to change for the women organizers. This was one of the main reasons why the women decided to advocate for educational institutions. For example, Rosa, a parent advocate, stated, “Before we started [organizing SENESE-NGO started in 1990], people had the archaic attitudes. You have children with disabilit[ies] and the reasoning is that you have done something wrong or naughty and you keep them hidden away at home.”

Rosa’s comment also speaks to her experience as a mother of a child with a physical disability. She was at the forefront for starting Special Needs Education/Inclusive Education or SENESE, an NGO that formed in the 1990s to advocate for mainstreaming students with disabilities in regular schools. Although this goal met some resistance, Rosa and a few other
parents and educators were able to establish services and programs for their students successfully. In the first year, SENSEE collaborated with a local private elementary school and eventually became an independent organization. However, lingering biases and shame associated with embodied differences continued to drive the women to be advocates and agents of change for the disability community. Afamasaga Telesia suggested:

There was a lot going on in the villages. *Ma* (shame); or *fa’aali mai tamaiti* (showing their children) to the public. Children with special needs were a curse and that sort of mentality in those days. The foundational work that we started off was meant to get the people [with disabilities] recognized. There was a need to take away the attitude of curse from their fagau or children [with disabilities].

(Personal communication, January 28, 2013)

Such stereotypes of people with disabilities continued to exist, but the women were even more determined to change the negative language and derogatory phrases used to describe people with disabilities. Lisa, a former member of Loto Taumafai School, continued to “Raise awareness by not using words like ma’i (sickness) but instead using terms such as “mana’oa fa’apitoa” (special needs). The rephrasing of these conventional, stigmatizing words also helped the school staff to understand better the implications of everyday language. For instance, words such as *ulu ka’e* (broken head), *valea* (stupid), *tamaiti mama’i* (sick children), and *vale* (crazy) were often used to describe people with disabilities that commonly circulated at the time.

The use of derogatory terms and phrases for disability reinforced ableist understandings of bodies. Sharon, the current principal of Aoga Fiamalamalama School, remembered that the “names for kids with intellectual disabilities were *kamaiki mama’i* or sick children, *kamaiki e*
leaga mafaufau (children with bad brain, valea (stupid), and ulavale (naughty)).” (Personal communication, January 30, 2013) During our conversations, she reiterated the challenge of changing parents’ views toward their own disabled children—from broken and intellectually limited to students who were smart. In addition, she had been working hard with her school staff to implement behavioral management approaches, such as talking to the students and helping them to understand their feelings. She is very optimistic that teaching philosophies and parenting approaches are slowly changing. She pointed out, “words [usually negative toward people with disabilities] have consequences.” (Personal communication, January 30, 2013)

Sua has been teaching at the Fiamalamalama since its establishment and one strategy that she used with both parents and staff was humor, particularly when teaching the staff “how to deal with student behavior and discipline.” Sua encouraged parents to refrain from spanking their children and to talk to their children about their behavior. From this perspective, Sua is starting from a position of presuming competence (Biklen and Burke, 2006), in which she assumes that students are smart and capable of understanding their behavior. The compounding of attitudes and reactions to such negative views toward people with disabilities also affected other spheres of the community. The women worked on multiple fronts to address negative perceptions of disabled children as unproductive citizens and to demystify negative views of differences. Efforts to change attitudes also involved people in leadership roles.

Networking with government officials and international organizations was an activity that the women organizers felt was very important and useful to their cause. However, working with officials in leadership roles was sometimes difficult, as many of them held stigmatizing and patronizing views of people with disability. Since the education of people with disabilities was a low priority, government officials and the formal policies they enacted also reflected such
attitudes. Unjust practices and everyday bantering toward educating people with disabilities drove the women’s organizing efforts and struggles toward “inclusive” education. To clarify here, the term inclusive education at the time meant having students with disabilities in formal schools. The details of whether these schools should be regular or private schools were unclear. For the women organizers, their idea of “inclusive” education was about having students with disabilities attend formal school.

Their goal of changing attitudes and perceptions of disability was a difficult task, as they were trying to engage all the levels of the community, from government officials to the local village and family members. As Sisi suggested:

A lot of people thought it [disability] was a curse. We worked on changing public awareness. A lot of it was finance too, because if you live in kua (rural areas), it's a long way to come and they can’t travel by themselves. They need buses to come to school. (Personal communication, February 7, 2013)

Sisi brings up an essential point: the women were also struggling with the issue of spreading the educational resources and changing perceptions throughout the islands. Most people who lived in the rural areas did not have access to adequate health care, schooling, or modern life necessities because of their physical geographical location. Because Samoa’s current configuration continues to reflect colonial structures of governance, the village of Apia designated as the “town” area where all of the stores, government buildings, and schools were centralized. Such colonial urban planning and logistics put people living in rural areas at a disadvantage.

The women also struggled with whether the school should stay located in “town” or have moved it somewhere else. In the end, the organizers established the schools in the town area, as
this was where the majority of resources were located, where they could procure space, and where most of the women lived close by. Finally, when the public announcement of the school’s opening occurred, people with disabled family members gradually began to gravitate to the school. Fili remembered when they first opened the school and people showed up with their children. Fili recalled the excitement at the time: “The general idea was that people hid their disabled children. People began to eventually come to school, provide things for them to do, and [believe that] they can be something.” (Personal interview, February 5, 2013) Of course, the attendance of students with disabilities in schools like Fiamalamalama and Loto Taumafai did not completely change negative attitudes toward them, but was an important start to growing the seed of disability awareness.

**Conclusion**

The organizing efforts by the women and their allies spoke to community needs at the time. Their work intertwined multiple histories and events, both locally and transnationally. The advocacy for the schools came from a grassroots and inclusive organizing standpoint and included people with disabilities in forming Fiamalamalama and Loto Taumafai. Such inclusive praxis serves as a model for forming schools, organizing as a collective, and understanding the importance of solidarity as a group advocating for the same cause. However, I also argue that in the end, the women organizers balanced cultural and social protocols in order to accomplish their goals of creating schools for the disability community.

In retrospect, the meanings of inclusion in schools have evolved since these schools began and definitions of activism have remained contested. The fact remains, however, that individuals with disabilities have a place that they can call their school. Considering school as a space that is inclusive of all people’s differences is a questionable concept, especially when
coming from a decolonizing praxis. In this study, unpacking dominant ideologies that codified the educational practices of students deemed educable in colonial structures such as formal schools can greatly influence how we negotiate educational policies and school history and formation. Doing decolonial work, is about recognizing inequitable patterns of exclusion and dominant views that justify them. It is also about shifting paradigms in the field of education in how we critically think about students with disabilities as sanctuaries of knowledge and as agents of change. More importantly, decolonial praxis is about the even distribution of resources across communities and transformation. The wider implications of having schools for students with various abilities can potentially lead to effective strategies and practices for addressing issues of poverty, unemployment, and pity that indigenous people with disabilities struggle with everyday. These struggles are, in fact, still widespread in the global South. Thus, the project of decolonization is not just about reacting to the needs of the time, but also continually situating the future of nations and the responsibilities of those in power to promote equality and mutuality. The women’s advocacy and organizing approaches had far-reaching effects on the island. For one, students with disabilities became more visible in formal schools over time. In other words, these schools served as stepping-stones for greater inclusion. Second, the advocacy forced the education department to acknowledge the pressing needs of the disability community to be included in schools. Thirdly, people with disabilities were educated despite negative attitudes and low expectations for their success. In light of all these changes at the time, the women organizers remained committed to the continual education of all students. The next chapter focused on belonging in education and juxtaposed this goal with the experiences of two former students, Lisa and Sasha. The implications of Lisa and Sasha’s story are about access, tolerance, inclusion, and ableism and what can we learn from their experience.
Chapter 6

Stories of Belonging by Former Students

To understand better how students’ negotiated questions of belonging, agency, and resistance at the Aoga Fiamalamalama and Loto Taumafai Schools, I focus on the stories of two women with disabilities, Sasha and Lisa, former students of the schools. Both women negotiated a range of gendered and power dynamics in their communities, and their stories speak more broadly to the experiences of many other former students and members of the schools. Sasha and Lisa self-advocated and asserted their cultural and personal understanding of disability, advocacy, and language. They demonstrate that many of the issues they raised about disability and belonging is also about gender: the two factors interact and must be examined together to better understand our ways of thinking about differences and able-bodied privilege.

My goal is to highlight the complexity of Sasha’s and Lisa’s lives and to illustrate how their particular stories are about individual independence and co-existent with interdependent relationships with family members and friends. Their stories offer a point of intervention, challenging our ways of thinking about exclusion, stereotypes, citizenship in Samoan protocols and ways of knowing. Furthermore, I argue that the cultural and national discourses of belonging in Samoa are not the same for all of its citizens. Especially in the case of women with intellectual and physical disabilities: in other words, despite a general cultural ethos of collective belonging, love, and responsibility, it is also the case that some people have still been left out or treated as lesser due to both gender and disability.
The first section of this chapter focused on the notions of inclusion within the Samoan community. Specifically, I examined the stories of former students and the manner in which the schools’ student demographics changed over the years. For the next section, I shared Sasha’s story, a former student of Aoga Fiamalalama and Loto Taumafai. Sasha’s experiences reflect her resistance to Samoan authority and traditional roles for women. Likewise, Lisa is another former member/student/staff of Loto Taumafai and this is her story at home, work, as a mother, disability advocate, and an educator. I also explored the use of stigmatizing language that marginalizes people with disabilities. Finally, I concluded by analyzing the broader meaning of Sasha’s and Lisa’s stories in the areas of access, tolerance, ableism and inclusion.

**Former Students of the Schools**

**Student Outcomes**

The founding students of Aoga Fiamalalama were Gele (Sina’s son), Olioli (Fa’atonu’s daughter), Sasa (Dr. Tanielu and Mary’s daughter), Norman, and Hone (Sina, personal communication, August 22, 2015). According to the women organizers, the founding students started in the preschool classroom and then transitioned to Aoga Fiamalalama. Sina related, “Most of the founding students were diagnosed with mentally retarded, developmentally disabled, and Downs syndrome.” (Personal communication, February 5, 2013) These students stayed at the Fiamalalama campus for most of the day. Sharon, the current principal of Fiamalalama, shared that some of the students who graduated have returned to work for the school. For example, Sharon said, “Many of students are in their early 20s, they don't have jobs or continuing education places [to go] so when our budget allows us, we try to hire them as educational assistances or office help.” (Personal communication, January 30, 2013) Likewise,
Loto Taumafai also hires former students to work as paid staff. For example, Sasha and Lisa both worked at their respective schools after graduating. According Lisa, “There are many people with disabilities who have no jobs and we want to work.” (Personal communication, February 7, 2013) Lisa’s comment is suggestive of the ongoing difficulties faced by the disability community who have no other option after high school. The work force in Samoa is limited and employers seldom hire people with disabilities. In addition, the Samoan government does not offer disability benefits or monetary assistance to people with disabilities. The responsibility is on families to care for their loved ones. Thus, people with disabilities, especially women with disabilities in Samoa continue to be a marginal group in the community. As Lene (2004) revealed in her study about women with disabilities:

Most women with disabilities in Samoa are among the poorest of the poor and are often living in vulnerable and at risk situations. Because of the historical lack of statistic information on the Status of Women with disabilities, their needs have become invisible and have not been addressed in development initiatives. A significant number of women with disabilities who perceive themselves as potential and willing contributors to family and national economic activity are instead referred to the margins of society where they maybe perceived as a burden. The result can be devastating, both to the individual and to the economy. (p. 12)

Unfortunately, unemployment continues to be a struggle for everyone in the community. The schools in this study have mediated the need for educational facilities that serve people with disabilities at the K-12 grade levels, but now more programs and services are necessary at the postsecondary level.
Student population over the years

Fiamalamalama and Loto Taumafai over the years have changed in terms of student demographics. As educational institutions, both schools have an “open” policy of enrollment, meaning any student can attend the school without having to take an entrance exam or meet an eligibility requirement. Surprisingly, the schools opened to non-disabled students. According to Sua, some non-disabled students attended the school, but usually for a short period (while in transition to another school). Lupe related attending school with disabled folks was not a popular choice, the stigma of not “wanting to be associated with the ula ka’e (broken head) kids at the schools” was often a reason cited by non-disabled students (Personal communication, January 23, 2013).

The student demographic also changed due to two factors: (a) leadership in the schools; and (b) students with disabilities have medical needs that affect their attendance in schools. School leadership and the teaching staff are the foundation of a school. As Tina, suggested in our conversation, “Without teachers there is no school.” (Personal communication, January 31, 2013) The principal of the school also takes on a critical role in implementing the mission and services of the school. More importantly, the administrative staff is influential in the choices of curriculum and praxis disseminated in the schools. For example, Fili shared a story about Donna, a new principal for Loto Taumafai in the mid-1990s; when she started working at the school many deaf students chose to attend Loto Taumafai for their education. The reason for this shift in student attendance was that Donna was a trained deaf and inclusive studies teacher from Australia, and she was active in the community. Donna was inclusive of deaf students because some were “left out” in schools because of the lack of access to sign language. Such exceptional and inclusive politics brought “Students from all over the island…to be at Loto Taumafai”,
shared Fili. More importantly, as Sisi stated, “Donna was also an advocate for inclusive education and believed that deaf students can be successful in school if they are given accommodation tools like sign language.” (Personal communication, February 5, 2013) Through Donna’s leadership and the other teachers’ advocacy, Loto Taumafai also taught Australian Sign Language to all of the students and staff. As Leta’a, the current principal stated, “Sign language allows all the students and staff to communicate and no one is left out.” (Personal communication, March 11, 2012) For Aoga Fiamalamalama, their second principal, Agnes, also supported the attendance of student with learning disabilities. The school leaders endorsed this teaching philosophy and many students with learning disabilities attended Fiamalamalama, changing the student dynamics. Agnes was not interested in teaching vocational skills--sewing, handicrafts, or art. Instead, she implemented a regular school curriculum of reading, writing, science, and language arts. According to Sisi, “The handicraft [equipment] was thrown out. She wasn’t interested in the mentally handicap, she was interested in teaching at a normal school. So whatever didn’t suit her, she threw out.” (Personal communication, February 7, 2013) Although, I do not agree with Fili’s assessment that Agnes did not carry out the school’s mission, I think Agnes was trying to change the school’s environment so that it reflected government school classrooms and students’ need.

According to the staff at the schools, students’ attendance was also sporadic because many of the students had medical and health needs, which kept them out of school for several months. As Sua and the school principals reiterated in our conversations, consistent student attendance is the biggest challenge they faced. As Sharon stated, “its hard to be consistent when students don't come to school daily because of fa’alavelaves [or family emergency-death, wedding, travels] or illness.” What the school staff shared with me that many of the students
frequently traveled back and forth between Samoa and New Zealand during the school year, which also adds to the difficulties in teaching students, maintaining attendance, and accounting for student progress. When I asked the staff if there are specific reasons for the students’ travels, they noted that it is usually for visiting family, going on holiday, or medical check-ups. This point was interesting because it identified the type of students who attended the school, assuming that these are privileged students with means to travel throughout the year. Another observation here is that the students traveled during the school year, which meant that attending school was a secondary priority as some students were dealing with life threatening conditions. Another reason also pertains to the medical and health issues faced by the wider disability community. As limited as the medical approach to disability is, most people with disabilities continued to seek medical services, which afforded them a level of comfort and an improved quality of life. Students’ absence from school has other implications in terms of the student’s academic progress. I wondered about how family members accounted for the student’s missing school and in making up these school days. In my interviews, many of the parents tried to keep their children in school for the entire school. Of course, students sometimes have to miss school because of pressing medical concerns and family obligations. For instance, a former student I was planning to interview for this project had an emergency heart surgery and departed for New Zealand. Sadly, this student was gone for four months while recovering from his surgery. The teaching staff and parents also conveyed that other reasons attributing to the change in student population are the lack of transportation, overdue tuition fees, and lack of student interest in attending school. The motivation aspect of attending school was another factor for student absences. When I probed the women organizers to explain further this part, two of them mentioned that students outside of the school often teased students at Fiamalamalama and Loto
Taumafai for going to school there. Sharon shared an incident when the Fiamalamalama students were on the school bus and some kids were teasing them as they passed by. The next day, Sharon prepped her students to respond to the mocking comments of vale or stupid, by saying, “O ke le valea, o lea fo’i oute alu i le aoga pei o o’e” [or I am not stupid, and like you, I am going to school too]. (Personal communication, January 31, 2013)

**Student Options after School**

For students at Fiamalamalama and Loto Taumafai, school is “over” for them when they reach there 20s or when they decide to no longer attend. These are not firm guidelines or enforced policies for people with disabilities, as shared by the women organizers. Here, the students and their families have the autonomy to do whatever suits them, as there were no formal educational mandates about school attendance for people with disabilities.

Today, some of the former students of the schools work at low-paying jobs, stay at home, or work at Fiamalamalama or Loto Taumafai. The students who often find jobs outside the school usually work as janitorial staff at McDonald’s fast food restaurant, local beauty salons, or helping out with the family business. In Sasha’s case, she is a representative for the Samoan International Special Olympics Games and an honorary disability advocate. She went to Greece in 2008 and according to Lani, brought home two silver medals in track and field. Besides this amazing role, Sasha also works part-time at Fiamalamalama as an office assistant. As Lani related, for the most part, she likes working but on some days, she refuses to go.

Unfortunately, there are no formal vocational internships, regional centers, or job opportunities for student in their early 20s to do. Both schools pursued this area actively to extend their services. They specifically intended to meet the needs of former students by applying for vocational grants or by hiring the students to work at the school. As Foa, one of the
local disability advocates shared, “train[s] the disabled community to voice their needs, advocate for themselves, speak directly and frankly about what they are advocating for, because sometimes the truth hurts [services and needs for people with disability].” (Personal communication, January 26, 2013) Their organization NOLA or Nuanua O Le Alofa is another NGO staffed by people with disabilities. Foa’s comment captures the attitudinal barriers that the disability community continues to encounter when seeking basic social services. He succinctly puts it, “[In relation to jobs] many people in the disability community are marginalized by society and discriminated against.” (Personal communication, January 26, 2013) This continues to challenge the disability community and their allies, a task that Foa and his allies are working to remedy.

In the next section, I focused on Sasha’s story. Sasha’s experiences capitalize on the discourses and concerns about how her family support network helped her succeed.

“I’m quite bright!” Sasha: Former student

Sasha is a former student of the Aoga Fiamalamalama and Loto Taumafai schools. In the mid-1980s, she attended a separate school from her siblings, because none of the public schools accepted students with intellectual or physical disabilities. Her medically diagnosis is mental retardation (MR) and other health impairments. She can verbally communicate with people, but is very selective with whom she engages. Her mother and father verbally answered most of the questions I asked during our interview or talk story sessions. Doing collaborative interviews required trust, which meant having a prior relationship with the participants was key to having meaningful conversations. Since the goal of interviews is to understand how the person you are interviewing thinks, I was prepared to be flexible and redirect my focus on the opportunities the interview situation presented (Bogdan and Biklen, 2007, p. 106). For most of my interview with
Sasha, I was unprepared for her to be nonverbal. Therefore, the loose interview guide incorporated in my interview procedures afforded me some flexibility and structure to ask questions that I hope would show some of the difficulties in Sasha’s life, what was important to her, and what was happening in her life now. Moreover, this interview approach of asking multiple participants questions seemed more effective since I was regarded each person in the interview as an expert.

At the time of my interviews, Sasha was 32 years old and lived with her family. I have known her since she was a young girl. Her mother Lani and I are cousins. Our family dynamics also helped with the interview process, as this is the first time Sasha has agreed to talk to anyone about her school experiences. In exploring Sasha and her family’s experiences with the two schools, I was also mindful of the questions about the roles of participants in interviews, research methodologies, and the ethics of attending to the “voice” of participants. My purpose for speaking to former students meant that emancipatory approaches were central to conducting a research project with people with intellectual disabilities, given that such practices have been fairly limited (Welsby and Horsfall, 2010). The emancipatory paradigm stems from the gradual rejection of the positivist view of social research as the pursuit of absolute knowledge through scientific method. As Oliver (1992) suggests, “the emancipatory paradigm, as the name implies is about the facilitating of a politics of the possible by confronting social oppression at whatever levels it occurs” (p. 110). Thus, “the issue about emancipatory research paradigm does not focus on how to empower people but, once people have decided to empower themselves, what research can we then do to facilitate this process” (Oliver, 1992, p. 111).

My interview sessions with Sasha were notable because she used different modes of communication to answer my questions (or not). For one talk story session, Sasha
communicated with me through her parents. The next interview session she listened to her headphones and semi-communicated with me by pointing to a newspaper she was reading. Throughout these other encounters, she would also text message me from her mobile telephone. At one interview session, she talked to me the whole time about a popular Filipino soap opera on TV. For the session in which Sasha’s parents were physically present, the procedure of the interview often consisted of me asking her parents the questions, who then relayed the questions to Sasha for her answers. Throughout the interviews, Sasha did not want to stay seated during our talk story sessions. She preferred to walk around the living room or walk up and down the stairs while we were sitting and talking. Walking around the house while adults are seated is a highly frowned upon in Samoan culture. In fa’a Samoa (Samoan way of life), strict protocols, such as walking around while others are seated, is interpreted as rude or disrespectful. However, Sasha’s family recognizes her need for movement and makes her behavior an exception to the rules.

During the interview, Sasha either would shake her head from left to right in disagreement, or nodded her head up and down in approval of the answers that her parents were saying. If she wanted to explain her answers further, she would whisper in her mother’s ear. Her mother would then explain Sasha’s answers while Sasha attentively listened and approved the content her mother shared. Thus, although I was relying on her parents in the interview, Sasha made sure that I knew she authorized the content; thereby ensuring me that, she was cooperating in the telling of her story.
School Experiences at Lata School

Sasha’s school experiences poignantly reveal issues around disability, ma’i, and education. When Sasha started school, her parents enrolled her in a program at a private elementary school. The idea was that Sasha would eventually attend school with other students who did not have disabilities. Sasha and her parents initially had inclusive goals, but these changed as she progressed in school. Sasha had a complicated journey in both the Fiamalamalama and Loto Taumafai Schools. Although she was not one of the founding students of the schools in the 1970s-80s; her experiences at these institutions in the mid-1980s-1990 are worth examining to understand better the complex advocacy work done by families and by people with disabilities.

In the mid-1980s, Sasha attended Lata School, a private elementary school. Her physical presence at Lata School did not go over well with the rest of the school. Many parents believed that their kids were too “smart” to be affiliated with disabled students. Some even pulled their children out of Lata School in protest. However, it was the advocacy and persistence of parents of students with disabilities that finally permitted a small group of students to attend. As Lani recollected, Rosa and Seta, two mothers of children with disabilities, started SENESE, a special

15 Actual names of people and places have been changed to protect the confidentiality of the participants. Lata School is a pseudonym name for the school discussed here.

16 SNES stands for special needs education society was a registered organization in Samoa in 1992. However, it was pronounced by people as ‘seh-ne-she,’ as Samoan language usually has a vowel between consonants. Therefore, the “e” was added to SNES to account for the pronunciation of SENESE (www.senese.org).
needs education organization in 1992. SENESE was another NGO with a purpose of promoting mainstreaming of students with disabilities in regular schools.

One of the challenges for parent advocates and people with disabilities was convincing educators and schools that people with disabilities were worth educating. Another obstacle was the idea of disability contagion, meaning that if one associated with people with disabilities then it could be “catchy [contagious]”. Most of the Lata School parents frowned at the presence of students with disabilities and perceived them as “distractions” or as “taking away from” the “real” students. Of course, such ideas are not unique to Samoa: similar logics exist in the U.S., in which students with disabilities are still considered time-consuming to deal with, as teachers would have to provide more individual attention and thus take away from the learning time of other students (Ware, 2011). Most of the Lata School parents wanted the best for their children; however, having students with disabilities on campus was not the “best” approach according to the parents and administrators of the school. From the beginning of this partnership, the physical presence of students with disabilities on campus was unwelcome. Parents and teachers complained about having to share their classrooms and playground with these students. As Rosa conveyed, “they looked at some of the kids with disabilities and they had this idea that they didn’t belong… we had one kid with Down syndrome, a little girl with ADD [Attention Deficit Disorder], one boy with cerebral palsy, and another little boy with muscular dystrophy.” The idea of having the students at Lata School was that in the future the students could go into a regular classroom. So, as Rosa clarified “we didn't want to set up an organization that was gonna be there for a long time” (Personal communication, January 30, 2013). The goal was really to mainstream these students into the regular classroom.
The Lata school community met this goal with some resistance. The partnership negotiated by parents between the private school and SENESE was very much a “temporary” and “verbal” one, meaning that attendance of students with disabilities was contingent on the Lata School principal’s willingness to include these students. In other words, SENESE was a special education unit in Lata School. Lani described the rented space in the library of Lata School designated for the “special needs” section. Rosa explained, “We only had five students…with five parents who got together and started the school. We told the principal that we were getting our own teacher from the U.S. Peace Corps where we applied for a special education teacher.” The verbal agreement between SENESE and Lata School was that they would provide their own teacher for “their” students, and in exchange, the SENESE’s teacher would work with Lata students on remedial reading and math skills as well. Further, the mainstreaming of the SENESE students could occur for classes such as music, sports, and art. The benefits for SENESE may seem uneven but, as Rosa suggested, “it was the best they could do at the time.” (Personal communication, January 30, 2013)

For Sasha, her school experience at Lata was short-lived due to one particular incident combined with various other experiences of intolerance. When she was eight, she “voluntarily” left the school. The story told by her mother revealed that there was intolerance for differences among the school staff and students. Sasha had a bowel “accident” in her pants. In this scenario, it is difficult to know if Sasha “chose” to have an accident in her pants, asserting her agency, or if this was something, she could not control. In any case, because the school did not have a shower, she went to the garden hose and washed herself. Unfortunately, the water went downhill to the playground area where other students were playing. The students teased Sasha by saying
to her, “You stink, you pupu.” Then, the principal called Lani to come and get Sasha from school.

Upon arriving at the office, Sasha seemed visibly upset. When Lani asked her what happened, she cried and pointed to the principal, “E aikae, eat shit, you bitch, I’m not gonna come back here. They [students] called me names!” (Personal communication, January 5, 2013) Sasha’s angry comment directed at the principal is atypical of principal/authority and student/obedient relationships in Samoan schools. In most cases, students accept “blame” to convey respect to principals. However, Sasha felt that the school staff had failed her, as they had the authority to discipline the students who were teasing her, but instead they did nothing. Sasha also understood hierarchical power relations, as she knew that the principal was the person in charge and could resolve such conflicts in school. Sasha decided not to return to Lata School after this traumatizing experience.

The principal informed Lani that she had spoken to the pule (principal) of Loto Taumafai School who had agreed to take Sasha as a student. The Lata School principal advised Lani to take Sasha elsewhere because other parents were complaining about Sasha’s “unacceptable” behavior. I would argue that encouraging Sasha to transfer schools is in stark contrast to Samoan values of inclusiveness and living in harmony. However, here the value of inclusiveness was in tension with hierarchical authority models and a rush to moral judgment against those who deviate from the norm.

In Sasha’s case, she was pushed out of Lata School. The implicit message that Lata sent to students like Sasha was clear; they did not belong in their school. The children at Lata did not learn the value of diversity and I would say that the school disregarded core Samoan principles of alofa. The staff showed an unwillingness to engage in teaching opportunities about tolerance
and acceptance, and instead put the blame on Sasha as an individual. Certainly, overlooking the issue of the safety of other students’ health must not occur: from a school administrative standpoint, changes happen if other students’ wellbeing or educational needs are adversely affected. However, I would argue that the school staff could have done more to accommodate Sasha’s needs, such as having a shower facility for her to use with dignity, or periodically assigning bathroom times for her.

The point here is that all students have different educational needs and an accommodating environment meeting these needs does not undermine the rigor of the school’s curriculum and would be more in line with Samoan values of collective family and belonging as well. The problematic idea of ableism, which asserts that all students must fit into a “one-size-fits all” mold were clearly at work here. Normative and normalizing approaches tend to extend to any student that do not resemble able-bodiedness, such as English language learners, students with chronic medical needs, and students with visual and physical disabilities. This particular incident involving the water hose reveals the intolerance that disabled students and their parents and staff at Lata School and within SENESE faced. It indicated the ideological and pedagogical differences among school staff, parents, and students. Lani reflected on this incident as the one that opened the floodgates for Lata School parents of non-disabled students to complain: they did not want the ula ka’ea (crazy head) children there. Immediately after this incident, Sasha transferred to Loto Taumafai School.

**Loto Taumafai School**

Sasha attended Loto Taumafai School, but only very briefly, in the late 1980s. As Lani described Sasha’s experience:
Not long there [Loto Taumafai], as you know, *e ese lava le ... e ese foi tamiti e aoga ai* or [different students here], Sasha had a different disability capacity from the other students attending school. No facilities to shower when her *manava is ma’i* or [diarrhea] no shower facilities when she has diarrhea. And she is uncomfortable. (Personal communication, December 12, 2012)

In other words, the same thing happened: she had a bowel “accident” and there were no showers on campus. She had to leave the school. And, again, the school’s *pule* (principal) asked that Sasha be taken elsewhere, in this case to Aoga Fiamalamalama or IHC school. Ironically, the idea of inclusion in the schools was not honored in Sasha’s case; as the mission of Fiamalamalama and Loto Taumafai was precisely for the inclusion of students with disabilities. Evidently, Sasha’s case was a difficult one for the schools to handle, and health regulations would not allow for these incidents due to sanitation and safety guidelines.

**Aoga Fiamalamalama School**

Around the early 1990s, Sasha arrived at Aoga Fiamalamalama to work with Sera, the *pule* (principal). For the first six months, Sera worked hard to build Sasha’s confidence at school and her social skills with other students. She was withdrawn and very shy, rarely spoke to anyone, and preferred to be alone. Sera explained to Lani, “We almost missed Sasha”, meaning that when Sasha arrived at Fiamalamalama, she was displaying behaviors of avoidance and disengagement from her surroundings. Sasha was starting to create a space that she could withdraw into to disengage with people around her at school. Perceptively, Sera suspected this was due to Sasha’s traumatic experiences of being “kicked out” and told that she was a “bad girl” at her previous schools. Sera further explained:
You know Lani, *talanoa atu mama ia o’e, toetiti lava* [I’m talking to you frankly], we almost missed Sasha, she almost became mentally handicapped. She got to the point where she is starting to do void [avoid] and separate herself from others, like a *pa sima* [concrete wall], where no one can touch her or harm her. She created her own world where she can escape. *Ua fiu* [she is fed up], and no one cares. She is just escaping to her own *lalolagi* [world]. Everything else *e leiloa a si teine ma cope* [she doesn’t know how to cope]. (Lani, personal communication, January 23, 2013)

At Fiamalamalama School, Sasha also worked closely with another teacher, Sua. Ms Sua as the students called her, often emphasized the need for Sasha to independently use the bathroom in school and at home. As part of the school curriculum, Sasha learned to take care of personal hygiene needs. Sua viewed her role as a teacher as a personal one, “*O lou alofa ia i tamaiti,*” or I love these children (Personal communication, January 5, 2013). Through Sera and Sua’s teaching, Sasha became independent in using the toilet while at school and sometimes at home. According to Lani, Sasha’s success in learning independent life skills occurred from her teachers at Fiamalamalama. Their patience and willingness to work with Sasha made a difference in her life. As a result, she was able to attend her friends’ birthday parties outside of school and be around her peers. Sasha’s new independence also empowered her to articulate her opinions and needs.

Lani also shared that Sasha learned how to read from a teacher named Marley [a teacher from New Zealand], who briefly worked at Aoga Fiamalamalama. In this curriculum, the students learned how to read by using a computer program. For example, if Sasha completed a puzzle, a video of a dancing ballerina appeared. Sasha completed all the lessons because she of
the mesmerizing affect of the video. Lani recalled one of Sasha’s classmates’ responses to her excitement about completing a level of the reading program. He would say, “Oh Marley, there she goes again, she lost her marbles. There she goes doing her ballet, can you make her stop?” Marley would respond, “Oh let her be, Sasha has completed a puzzle, stop minding Sasha and you can complete the puzzle too” (Lani, personal communication, December 28, 2012).

Notwithstanding her reading progress, Sasha still found it difficult to tell time. For example, her mother mentioned an incident in which she had to stress to some of Sasha’s friends that she struggles with telling the time. As Lani related, “She can’t differentiate today, tomorrow, and yesterday.” (Personal communication, December 29, 2012) Therefore, when planning events, Lani often reminded Sasha’s friends to call her and arrange the details regarding the time and day of the meeting. Then she would work with Sasha to understand what time and day she must get ready for the event. Lani used monthly calendars to help with the days, dates, and time. Recently, Sasha used her cell phone to look up the time and date; this seems to be working out for her.

Sasha’s experiences in school are disheartening at times, but also informative for educators and the broader community. Her exclusion from the previous schools was sad, because they did not bother to teach Sasha anything. She went from school to school thinking that something was wrong with her. However, through the teaching and patience of educators at Fiamalamalama, she proved to others that she could learn reading and life skills. More importantly, the teachers started with the fundamental objective that she belonged in their school and was capable of learning, and these simple guidelines built Sasha’s confidence. In result, she learned to use the toilet and communicate her needs.
Family Experiences

Sasha is the second eldest child of six siblings. Her immediate family consists of four brothers and one sister. Her father noted that Sasha is an easy-going person. She is also very independent. Sasha’s father said that he disciplines her by lecturing and taking away her mobile phone credit.

Sasha is independent because her family supports what she chooses. In her family dynamics, she is an active member of the family and loves being around people. Sasha hangs out with her parents, but she also enjoys being with her siblings. Noticeably, outside of the family dynamics, Sasha’s family is very protective of her. She often attends all the family events and sometimes will go out to a nightclub with her siblings. Her mother shared that when Sasha was younger, her grandfather, who has since passed away, adored her. He would take Sasha and her older brother swimming off island to Savai’i, another island in the archipelago, and drive them around town. She remembered when Sasha was about five years old, and she tried to drive the family van parked in the carport. She drove right into the ravine on the side of the house. Luckily, she was not hurt and the car not damaged.

Sasha lived with her maternal grandmother, a retired educator with whom she shared a bedroom. Lani told the story of Sasha’s annoyance with her grandmother who was “pretending” to cry. Sasha asked her why she was crying and her grandmother said that someone took her ten dollars for her lotto ticket. Her grandmother was also playing a trick on her, because she knew that Sasha had her money. So, after a day of seeing her grandmother “pretend-cry” every time she entered the room, Sasha eventually threw the ten dollars back to her and said, “Ia kago lea e ai” [or Here, now eat it]. The entire incident tickled her grandmother and enjoyed teaching Sasha a lesson about taking someone else’s things (Personal communication, January 5, 2013).
The lesson here is that Sasha is more than capable of understanding her role in the family and her relationship to people around her. Sasha also understands her role in taking the money as something that is unacceptable. She reluctantly returned the money to her grandmother but she learned about people’s feelings, especially when she takes something that does not belong to her. Sasha is independent but also interdependent on others in her family. Lani shared that Sasha’s sometimes can be difficult with her siblings. For example, Sasha fights with her sister. One time she threw something at her sister’s head, and her sister had to get stitches. With her brothers, she punches; head butts and bites them when she is mad. As Lani related, sometimes it is difficult always to take Sasha’s side when she is fighting with her siblings. Lani recognizes that Sasha is aware of her behavior and as her parents; we have to discipline her as we do with the other siblings. Lani remembered one time Sasha was in trouble for arguing with her sister, while her father was lecturing her. Sasha said to her father, “Fia mimi” [or I have to go pee]. When she went behind the wall, she flipped up her middle finger and showed it to her father. Consequently, Sasha could not use her mobile phone or the computer for a week. Lani related, “She has a lively sense of humor, but we have to be consistent in disciplining her or she will run all over us.” (Personal communication, January 5, 2013)

Sasha’s lively humor also engaged negative attitudes about ma’i (sickness) in her family dynamics. The following story illustrates themes of ingrained discrimination, agency, and openness to disability and transformation. Lani shared another story about her daughter, Sasha. Here, I highlight Sasha’s response to normativity and illustrate her resistance to deep-rooted beliefs about ableism.

According to Lani, “One day Matt, our grandson who is about ten years old, was at home with Sasha. He was talking on the phone with a classmate. His friend asked Matt who was
home with him? Matt replied, ‘O au ma lou aunty ulu ka’e’ [or It’s me and my aunty with a broken head!] Without skipping a beat, Sasha walked by Matt and flicked his ear. She said to him, ‘Don’t you ever talk to me like that, I’m quite bright!’ Lani related that it took Matt awhile to return to the house. When she asked him why he had not been around, he said that he was scared of aunty when she flicked his ear very hard and that she will fasi (spank) me next time. Although her family thinks of Sasha as ma’i (sick), she begs to differ with this outlook by asserting her identity as someone who is quite bright (personal communication, January 5, 2013). This intimate family story also demonstrated that people with disabilities have a valued place in the family. Along the way, Sasha’s involvement with the schools in this study empowered her to advocate for herself and assert her power as an individual who belongs in the family and community. Regardless of her idiosyncrasies, Sasha is an elder to Matt and she has the right to emphasize that identity. More crucially, she has the authority to discipline him and that is acceptable in the family domain. Likewise, the exchange between Matt and Sasha reinforced the Samoan value of respecting your elders, which theoretically trumps the “disability or ma’i” view of difference and weakness. This interesting exchange between aunt and nephew within the aiga (family) sphere is indicative of the complicated views on disability in Samoa.

As an aunty, Sasha exercises her authority as an elder to reinforce the roles to the younger generation who sometimes dismiss her as someone who is “crazy”. For example, she scolds her nieces and nephews when they are ulavale (naughty), and sometimes slaps them. Other times, she hisses at them like a cat and according to Lani, that usually scares them. Lani reminds Sasha to use her words to talk to the children instead of animal sounds. Lani related that the children will ask her when Sasha is not around, “Is there something wrong with aunty? She is weird sometimes!” She tells the children that there is nothing wrong with Sasha. However, on
the side Lani tries to talk to Sasha about her behavior of cursing at the kids, telling them they suck and shooing them away if they annoy her. I explained to Sasha, “Look here, don’t act like that. You are an intelligent woman and when you act like that your points go down.” Sasha will then respond, “Yeah, yeah, who cares; it’s only a joke!” (Lani, personal communication, January 5, 2013)

Sasha is also aware of the power dynamics within her family and her place in line according to social expectations. During my time with Sasha, she sat briefly on the couch, listened to our conversation, and then went upstairs to her room. I asked her mother what she does in her room; Sasha mainly watches television, listens to the radio, or “cocoons herself in her blankets” while the fan is on full-blast. Or, she sometimes reads the local newspaper, in which she finds the mobile phones that she wants to buy. She will then pester her parents and siblings to take her to the store to buy the phone.

Sasha also communicates verbally with her parents by telling them what she wants to eat, where she wants to go, and what she wants to do. Her favorite food is pizza. According to Lani, every morning when she was getting ready to attend classes at the local university, Sasha would ask her where she was going and what time was she returning. One of her other favorite tasks is to answer the telephone, and call people when no one was paying attention to her. She often called the local radio station to request a song or participate in whatever contest was going on.

Sasha is also technologically well informed and uses the computer at home. Lani related that she thinks Sasha may have a “photographic memory” as she can remember the passwords to emails and whatever someone was doing on the computer. In the past, while sitting on the couch next to the computer, she memorized Lani’s passwords to her accounts and then later on got into her email accounts. After this incident, Lani was very worried about Sasha’s well-versed ability
to use the Internet and get into other people’s email accounts. Therefore, Sasha could not to sit close to the computer while someone was working on it. In addition, Lani had to put strict parental settings on the computer and limit Sasha’s computer time. She may use the computer only when her parents are at home, but can be on her cell phone anytime because it does not have an internet connection. She does not like these restrictions or rules. She would say to her parents, “Yeah, yeah, whatever,” but abides by them. More aptly, Sasha’s well-versed use of the internet and technology are because of her education at school. She learned to read from reading program on the computer and she is confident in her ability to use electronic devices. She enjoys playing computer games and taking pictures on her digital camera. On the computer, Sasha edits her photos and sends them to friends and relatives.

Some of my interview sessions with Sasha were also through text messages on her mobile phone. Our communication routine and conversation usually started with Sasha text messaging me about giving her “$1,000,000 for her phone credit” (Sasha, December 20, 2012, Telephone interview). In reply, I texted, “Holy moly, where do I get that kind of money from?” She replied, “Hi aunty, misses, luv, and u coming over today, zzzzz.” (Sasha, Telephone interview, December 20, 2012). After texting back and forth about her day, I would then ask her a question about going to school at Fiamalamalama. Most times, she would not answer my questions, but would instead talk about text messaging and her phone credit. In another text conversation with Sasha: I asked Sasha, “What did you like about school [at Fiamalamalama]?” Her reply was, “I dun’t like sewing!” I answered, “What do you mean? Why sewing?” But, she dismissed these questions and went on to talk about the game that she was playing on her mobile.

What is fascinating about my text message interactions with Sasha is her resistance to answering questions about school. I am not sure if she feels “too old” to talk about school, or if
she does not want to engage these questions or recall these experiences. Therefore, many of the questions that I have about Sasha’s experiences in school I also asked her parents. Outside of an interview setting or talking story session, Sasha is usually very shy about talking in public. During family gatherings, she often listens to the conversation and will occasionally add a phrase or comment. Mostly, she prefers to listen to her music with her headphones on. I think Sasha’s perceived reluctance to answer my questions was her way of showing her agency to do as she pleases. I don't think it is an issue of comprehension of the questions because Sasha sometimes will reiterate my questions to her mother. For instance, Lani said, “Out of the blue she [Sasha] asked me if she was good student in school.” Lani chuckled at her question and wondered what prompted it. Finally, she remembered our conversations about school and realized that Sasha hears what we are talking about and maybe she is processing what she wanted to say. Despite the difficulties in interviewing Sasha, it was worth the efforts in trying to get perspectives.

Sasha’s story is a great example of having a supportive network that cares for her welfare in school and life. From her siblings to extended family, Sasha received the love and guidance that any person needs. More importantly, key people in her life empowered Sasha to learn and relate to others around her. Sasha’s story is also about understanding her as an individual with agency. “I am quite bright” a quote from Sasha’s conversation with her nephew who called her “my aunty ulu ka’e” is an example of her ability to self-advocate. Her story also highlights the frustrations faced by parents and family members in everyday school settings and life. The actions taken by these supporters to find solutions and negotiate these difficult spheres can potentially be a useful tool for others to learn.

The next section examined Lisa’s experiences in school, at home, as a disability advocate, and what can we learn from her journey.
Lisa and I first met in 2011 when I was conducting preliminary research for this project. In 2013, we reconnected when Leta’a the current principal of Loto Taumafai suggested that I contact Lisa again. Luckily, she generously agreed to share her story in this study. Lisa is a Samoan woman, mother, aunt, and sister with a physical disability known in common vernacular as brittle bones. She was eight years old when diagnosed with this medical condition, and she describes herself as being “wheelchair bound since.” Lisa indicated that her condition is hereditary from her father’s side, and the females in her family are often the gene carriers.

**Educational Experiences**

In terms of her association with Loto Taumafai, Lisa clarified that in the mid-80s, her role with the school “was [that of] a member not a student”. She considers herself a member because she did not attend Loto Taumafai exclusively. She also attended another school, St Mary’s College, an all girl’s Catholic high school, from 1987-1990. Lisa’s prior education experiences were in San Francisco and Honolulu, where she lived with her grandmother. Lisa, like some of the students traveled between the US and Samoa. For Lisa’s case, she lived in these places because it was convenient for her to receive medical services while she was around family members.

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17 Lisa’s use of the phrase “wheelchair bound” explains her interpretation of the condition that resulted in her becoming confined to a wheelchair. Conversely, the Disabled community seldom uses the terminology “wheelchair bound” because it implies that someone is stuck or bound to the wheelchair, as opposed to viewing a wheelchair as a mode of transportation or a means to mobility; which one would be stuck without a wheelchair but not within it.
Lisa returned to Samoa in the mid-80s and this is when her relationship with the school flourished. Despite the lack of physical access to the classrooms, she was encouraged by her parents to continue attending Loto Taumafai. Lisa explained, “My Dad wanted me to go to Loto Taumafai because that was the only physical disability [place] at the time; there was the Blind Society and Fiamalamalama for … intellectual disability.” Lisa went to Loto Taumafai throughout the year. She took courses in sign language, English, and typing while also taking courses at another school. Lisa chose to attend both schools because she enjoyed school. Loto Taumafai as Lisa indicated, “was a familiar school” and also became a home space for her. She met so many “wonderful staff members and parents there” who encouraged her to keep going to school. Loto Taumafai also met Lisa’s educational needs despite her long absences from school. For example, Lisa remembered one time she returned from Honolulu after having surgery, and the school year was almost over. She decided to only attend school at Loto Taumafai and use her time there to catch up on what curriculum she missed. In addition, she also took courses in sign language and English. St Mary’s College taught curriculum in English, science, math, and language arts, similar to other government schools. The culminating tests at the end of the school year often ranked student’s standings and this determined the classes they took the following year.

Lisa also indicated that she went to Loto Taumafai because she liked the extracurricular classes offered there: woodcarving, furniture making, and sign language. Lisa shared, “At Loto Taumafai, I learned American Sign Language and Australian Sign Language; the difference between American and Australian sign language is that you use one hand in American and two hands in the Australian one.” (Personal communication, February 7, 2013) She also received medical support (audiology, chiropractic, physio-therapy) from the school, which was not
offered to the public. From Lisa’s perspective, Loto Taumafai was similar to a “community center” organization. She wanted to be there and attendance was not mandated. Lisa’s case of attending both schools was atypical at the time because most students attended one school. Attending both schools also spoke to Lisa’s socio-economic status of having the means to pay tuition at both schools. Lisa had a sister who also attended Loto Taumafai and they both returned to work for the school after completing their undergraduate degrees.

Students who attended both schools paid for tuition fees. The students at Fiamalamalama and Loto Taumafai, I contend, came from middle to upper class families. The main point is that from the inception of the schools, people with disabilities from well off families were the patrons because they had the resources. It was not until several years later when government funding was more consistent that the schools were accessible to other parents. In additional to financial barriers, parents faced a lot of stigma and lack of support from the broader community about the schools. In lieu of their advocacy, Sina stated, “sometimes people laughed at us [women organizers] and say we are just as ulu ka’ea [or crazy] as our kids” (personal communication, January 25, 2013). Sina highlighted that people did not take them seriously…”fai makou a kala ula” (we were the butt of jokes), until international funding and resources started pouring into the schools.

**University Experiences**

For her last year of high school, Lisa was accepted into the National University of Samoa (NUS) for her University Preparatory Year or UPY. The UPY programs are college-prep courses that prepare students to enter a university or vocational setting the following year. Unfortunately, the issue of inaccessible classrooms also excluded her from attending NUS. As Lisa related, “My class was all the way up the hill. There were no elevators or footpaths to get
me there, just stairs. So that was put on hold and I took care of family stuff.” (Personal communication, February 7, 2013) Lisa stayed home and tried to figure out her next plan. In the meantime, she also dealt with health problems and often had to travel out of the country for these reasons. She added, “I didn't mind the break because I did not know what I wanted to study anyways.” (Personal communication, February 7, 2013) The question of access and belonging are not new to the disability community. In Lisa’s case, her presence at a higher education campus was clearly unexpected. The everyday, business-as-usual politics surrounding disability have systemically connected disabled bodies to environments like hospitals and mental institutions, rather than to the place that produced knowledge, universities. It is a relationship that is not only about exclusion and about inclusion, but is also one of knowledge, intelligibility, and projection of ideal spatial users. More importantly, Lisa felt that her disability was a “negative thing.” She shared that sometimes when she is really mad at people for making insensitive comments and staring at her, she told them, “Whether I am in a wheelchair or not, I still have the same rights as you.” (Personal communication, February 7, 2013) Sometimes people do not know what to say to her or react to her comments. Lisa views such incidents as moments to educate people by conversing with them.

By the mid-1990s, Lisa enrolled at the University of Hawai’i at Mānoa (UH) for two years. She shared, “I used to go to UH at Mānoa. I used to do translations there from Samoan to English. I was there in 1992, but didn’t finish my course because my Dad got sick and I returned home.” When Lisa returned home, she also returned to Loto Taumafai School as a staff member. She loved being at Loto Taumafai, a special place for her and her family. She enjoyed working with the staff and the students. But, most of all, this was her tautua (service), to give back to the school and others who had helped her along the way. As Lisa suggested, “I love this place [Loto
Lisa was a paid staff but as she related, all the staff there worked beyond the hours they were compensated for.

Lisa was able to attend UH Mānoa because her family had the resources to send her off-island to complete her foundational year. In talking to Lisa about the opportunities she was given to go to school, she attributes it to “God’s blessings to me and my family.” Her Christian faith has also contributed to Lisa’s ongoing advocacy in the disability community. Thereby, Lisa recognized her privilege in receiving an education and mobility to travel for medical services. She said, “I am thankful for my grandmother and family’s help.” Lisa is a firm believer of using what talents and resources you have to help others. As a young child, people called her “ma’i or sick all the time” a term that is reflective of someone inferior to the rest of the community (Personal communication, February 7, 2013). Lisa recognizes that people have to change their negative standpoints, which may alter exclusive policies and systems.

However, for most people with disabilities the limited income, lack of income, and/or paltry government assistance does not afford them such luxuries. In fact, poverty is one of the biggest barriers for most disability communities around the world (Campbell, 2008). A 1979 Department of Health survey estimated that the population of disabled Western Samoans in the region was one percent, or 1,000 out of 160,000 people living on the islands (Heath, 1987). These statistics reported that the majority of people with disabilities have a physical disability. The imprecise part of these statistics is that these numbers were only representative of 1979 because there were no other reports published in following years. The exact numbers of people with disabilities remain unclear before this date, making it an urgent task for social services agencies.
Family Experiences

Lisa was raised in Samoa for most of her childhood. She grew up with three brothers and two sisters. She also lived in San Francisco and Honolulu with her grandmother for several years. She attributes her successes today to her parents and grandmother who have always helped her. In addition, Lisa is a parent:

I have three kids, one is 23, my girl is 20, and my sister’s son is 4. I work for the National Council for People with Disability. We do advocacy work and we are the only advocacy institution organization in Samoa besides the service providers like Loto Taumafai, PREP, Fiamalamalama, SENESE. (Personal communication, February 7, 2013)

Growing up in a supportive family is something that Lisa is very proud. Her parents were adamant that Lisa and her sister continue to attend school despite their similar disabilities. As Lisa mentioned, “My mom always wanted us to go to school…My Dad and my uncle were the ones who enrolled me there [Loto Taumafai].” (Personal communication, February 7, 2013) In addition to her immediate family, Lisa was fortunate to have a grandmother who lived in Honolulu and she was able to live there while getting medical services at Shriner’s Hospital (specializes in orthopedic care). According to Lisa, “I have had five surgeries on my spine there.” Lisa shared growing up was difficult for her parents because she and her sister were often in need of medical services at the same time. Living in Samoa was not the best place for them, as the medical facilities on island did not have neuromuscular specialists. Therefore, her extended family’s assistance was crucial for her recovery and supporting her parents with their care. According to Lisa, her parents were optimistic and hopeful about her condition; they
“prayed to God that my sister and I would be okay” (personal communication, February 7, 2013).

Lisa shared that her family did not make her feel bad about her disability. As she conveyed, “I always felt bad that they [parents and family] had to take care of us.” Moreover, her parents were confident in Lisa’s ability to be self-sufficient despite her disability. Her family also reached out to medical professionals to learn about their condition, and found out that early detection was key. Because brittle bones are a genetic condition, Lisa reported that the next generations of females in the family do not have the condition.

**Discriminatory Experiences**

Lisa shared with me three particular experiences she encountered which reaffirmed her beliefs that there needs to be more work done to change people’s negative attitudes toward people with disabilities in Samoa. When Lisa had her children, her extended family helped her take care of them. Sometimes, she shared, “it was difficult to move around” so her mother was very helpful. At times when she was in public with her children, people would stare at her and according to Lisa, “wondered if they were my kids”. When people would hear the kids call her Mom, they usually walked away. Besides her role as a mother, and a working Mom, Lisa was also a caretaker for her ailing father. Her caretaker role in the collective family is a traditional marker of women’s responsibility to the “home”. Lisa accepts this role of caring for others, but simultaneously defies the stereotype of a woman with a disability as a “victim” or someone who is “helpless” and dependent on others for assistance. For example, a friend once asked her, “Who takes care of you?” Lisa replied, “I take care of myself and my husband helps me take care of my kids too.” (Personal communication, February 7, 2013) Some people find it hard to understand that Lisa can take care of herself and as well as her children and family. As Lisa later
explained in our conversation, people are curious about my life and sometimes I get mad at them. However, as an advocate, her goal is always to educate people about the community and hopefully, this experience will gain their support. Likewise, Lisa defies the tropes of women needing to depend on patriarchal guardianship from the state to survive. Lisa takes on the duties of mother, aunt, and daughter all of which symbolize her independence and capacity to care for others (as opposed to others caring for her). In this space, Lisa takes on a leadership role in her family. She is also the legal guardian and mother of her four-year-old nephew because her sister passed.

She also shared another intolerant experience when she worked for Polynesian Airlines. After working for Loto Taumafai for eight years, Lisa found a new job with Polynesian Airlines as a marketing officer. She recalled one incident while working at Polynesian Airlines:

When I first started working there, people would say to me, “Woi, o le a lea mea eke faigaluega ai? A’e le alu e nofo ile fale, lana o o’e e ma’i” [or Why are you working? You should be staying home because you are sick.] Lisa replied, “Ia sa’o otou ote alu i le wheelchair, ote le ma’i, ana ou ma’i, ua o alu ile fale ma’i,” [or Yes, you folks are right, I use a wheelchair, but I am not sick. If I was sick I would go to the hospital!] (Personal communication, February 7, 2013)

When she first started working, she remembered, “A lot of people would look at me and when I first started they used to watch me go by, and even when I go to the bathroom they still stare.” Sometimes people would ask her questions such as, “Do you work here?” Lisa encountered another experience, in which the staring eventually resulted in one person asking her, “Fa’apefea na e taele?” [or How do you shower?] She explained:
I had to reply because people have to know…they have to understand because they don’t have someone like me in their family. So I explained to her how I shower and who in my family helps me. Once the three months was up [of working at Polynesia Airlines], no one asked me [questions anymore], even the people in the building. (Personal communication, February 7, 2013)

Lisa’s answer demonstrated how staring could also be a conduit to knowledge. She makes “the unknown known, to render legible something that seems at first glance incomprehensible” (Garland-Thomson, 2009, p. 15). This idea of “legible something” is what drives Lisa to continue her advocacy in the disability community. She is hopeful that negative attitudes toward disabled peoples will change in the future. Nevertheless, Lisa’s presence and visible disability in a workspace that assumed to be only for “normal” individuals makes people uncomfortable. She dispels the dominant myth that people with disability are “unproductive citizens” and often depend on others for care and financial support (Baynton, 2006). For these reasons, she has made advocacy her life’s work by educating people, changing their negative attitudes, and creating dialogues with the community. She reiterated to me during our conversations:

Although a lot of changes has occurred since 2009, more kids with disabilities should be included in the mainstream [classrooms]…Advocacy is my labor of alofa, especially the work we do. (Personal communication, February 7, 2013)

Lisa’s experiences emphasize many complexities surrounding disability, culture, and inclusion. Her adverse experiences in schools and at work have greatly influenced her drive to advocate for people with disabilities. These experiences also encouraged her to be hopeful in implementing change within the community.
Lisa shared her negative experiences in school and home that influenced her decision to work in the disability community in Samoa. Lisa’s experience in school at the primary level was both challenging and rewarding. When I asked her to describe what it was like, she stated, “I remember when I was young, we used to be called ma’i, all the time. Even my own family would make comments such as, “Vai le keige ma’i” [or Be careful of the sick girl] (Lisa, personal communication, February 7, 2013). These early memories of being considered a ma’i person inspired her career choices. Presently, Lisa is a disability advocate in her community. One of her projects with the Nuanua O Le Alofas (NOLA) strives to change the outdated terms such as “handicapped” used to talk about people with disabilities. Rather, Lisa is educating the community on replacing the term ‘ma’i’ with the preferred term ‘mana’oa fa’apitoa,’ (special needs). Lisa’s advocacy and story echoes stories told by other disability advocates and people with disabilities about inclusion and agency. It is important to acknowledge the long-term emotional and discursive damage caused by stigmatizing and ableist language. Lisa hopes that dialogues about stereotypes and language can bring forth meaningful change.

Conclusion

Sasha and Lisa’s advocacy emphasizes the multiple complexities regarding the topics of disability, culture, and inclusion. Their agencies are examples of their fluid identities within the Samoan community. They embody the idea of border crossing (Mohanty, Russo, & Torres, 1991; Moraga and Anzaldua, 1987), which includes such representations and roles as mother, woman with a disability, and educator. As feminism increasingly recognizes, “no woman is only a woman” because she occupies multiple identity categories in terms of race, class, ethnicity, sexual orientation, language, religion, nationality (Spelman, 1988, p. 187). Sasha and Lisa refuse to be neatly labeled into an ableist category (Campbell, 2009), but travel in-between roles and
identities that are porous and flexible. Similarly, the women’s advocacy reflects the disability rights movement slogan, “Nothing about Us without Us” (Charlton, 1998). As James Charlton (1998) explained: “The slogan’s power derives from its location of the source of many types of (disability) oppression and its simultaneous opposition to such oppression in the context of control and voice” (p. 3).

Sasha and Lisa’s stories of negotiating belonging and advocating for inclusion are ones of hope: they also call for the Samoan community to continue to implement inclusion policies that change the institutions and attitudes that marginalize people with disabilities. Getting into a building or classroom are everyday occurrences for some of us, however, for people with disabilities this is often a greater obstacle if accommodating structures are not in place. For example, Lisa shared she is protesting and not going to the new shopping mall in town because it is inaccessible. She said, “They have a nice ramp in the front of the building, but there are no disability parking stalls in the parking lot and the restrooms are so small. I’m fa’alii [or tantrum] and not going there.” (Personal communication, February 8, 2013)

Sasha and Lisa contest inaccessible public spaces and both women are strongly pressuring the local businesses and buildings to become inclusive spaces. The physical challenges that Sasha and Lisa face are about access and acceptance into educational institutions. Even though these are two very different student experiences in schools, what stays the same is their experience of wanting to be included within their communities and their refusal of dehumanization.

Generally, not all people with disabilities want the same things, and advocacy work must also take into account such complexities and in-group differences in policy decisions. The trajectory of these stories starts with smart and disabled students in a dysfunctional school
system that cannot provide adequate services and programs to meet their needs. Sasha and Lisa’s self-advocacy speaks to their agency and to their power to challenge normative structures that limit their participation in educational, work, and public spheres. The hope is that making policy decisions to accommodate the needs of all peoples. Making changes in the educational system can in turn led to changes in policies and access. These are a few of the community tasks Sasha and Lisa continue to advance; their success in transcending policies and attitudes need recognition, since they have been recognized as the experts in addressing their own challenges and opportunities. For Sasha’s case, she also experienced the limits of inclusion--where even the creation of a school ensured access to schooling had limits to their imagining of what is possible. It was not until she went to the third school that teachers recognized the need to validate her presence as someone who belonged in school. Such teaching pedagogy led to Sasha believing in her ability to learn, grow as a person, and flourish academically. The main point here is that the schools’ mission to include people with disabilities was a springboard to reforming the education system. Yet, this idea also had limitations at creating spaces of belonging. As I show in this chapter, issues of both gender and disability biases enmeshed in Sasha and Lisa’s lives; the women separately dealt with disability discrimination as best as they could.

There is a need for more engagements with these positions of inclusion and belonging within the family unit and the wider community in Samoa. Sasha and Lisa’s experiences in school disrupt the larger (and romanticized) discourses of belonging and bring to surface how people with disabilities have not always been understood as part of the wider circle envisioned by nationalist discourses. Thus, examining these stories will broaden our understandings of multidirectional, layered, and oppressive discourses of power that reinforced normalcy.
Chapter 7

Conclusion

I started this research thinking that Aoga Fiamalamalama and Loto Taumafai were educational facilities that changed the landscape of the education system in Samoa. After 10 months of conducting 18 interviews, 6 months of reading over documents, and 4 months of visiting archives, my views on this history are more complicated and I realized that establishing the schools was not a linear process that ended with the school system. I now think that the changing of the educational system was a tiny part of the conversation that consisted of the broader social structures in the Samoan community. The relevance of historical, social, and cultural contexts is very much at the intersections of this conversation. This study has showed me that topics of exclusion and educability are not detached from economics, government policies, and cultural beliefs. All these contexts, driven by ableist ideologies supported by traditional cultural rituals and eugenics theories that continue to be normalized in schools and the community.

Reflections on Research Questions

Embarking on this study gave me a broad understanding of the two schools. I was interested in the initial conceptualizations of schools and the hope these creators had to accomplish in these schools. I wondered how the organizers gathered support from their allies and what obstacles they faced. In addition, I questioned how the opening of the schools affected the larger educational system and the lives of people with disabilities on the island. Ethnographic research allowed me to flesh out the intricacies of the cultural context and overt
ableism that the women organizers were resisting and pushing back against in advocating for these schools. They understood the need for formal schools to educate people with disabilities, and believed that changing educational policies, attitudes, and practices would deeply improve the welfare of people with disabilities. In framing the study, I began with four research questions:

1. What were the experiences of the disability advocates and former students at Aoga Fiamalamalama and Loto Taumafai schools?
2. How did the disability community and its allies approach disability as a critical lens to strategically navigate educational policies?
3. What were the Samoan notions of ma’i, education, and inclusion operating at the time and how did these impact the education of students with disabilities?
4. What factors influenced the social and power relations within these communities?

In the next section, I revisited each of these questions and summarize what I think are the most salient findings related to the questions. I end the chapter with some of the broader implications from this research study.

**Experiences of the Organizers, Advocates, and Students**

A consistent theme that the women organizers stressed throughout this study was the adversity they faced from the community regarding the education of students with disabilities. The women organizers’ unpopular agenda of educating people with disabilities did not fit the normative standards of education at the time. The wider community felt that resources were already limited and educating students with disabilities would be a “luxury” that the education department could not afford. Another theme was the finding of financial support to establish and
operate the schools. In terms of the former students, an ongoing theme from their experiences was that they wanted to “belong” in the community by attending school like their peers. This was a difficult place for the organizers to negotiate because even after the schools were established, the students were still isolated from their non-disabled peers.

**Disability and Navigating Educational Policies**

The exclusion of students with disabilities from an education system, was a normalized policy until the disability community began advocating for changes. The need to include and expand the definition of what type of students can attend school led to Aoga Fiamalamalama and Loto Taumafai’s establishment. However, the Samoan education system at the time did not have the resources to establish schools for disabled students. Thus, the women organizers used NGOs and international donors to solicit aid, which started the schools. The women organizers were perceptive in creating their own networks of support by collaborating with other education advocates, government officials, churches, and familial relations located at the local and global spheres. Their sharing of resources with these groups facilitated collaboration and raised awareness in the community. More critically, the women organizers’ solidarity politics of working with other women groups such as Christian churches, healthcare clubs, and local community organizations helped them to sustain their advocacy despite people’s negative attitudes. Similarly, the women organizers built strong social and cultural capital in the community through their advocacy and relations. In addition, the women organizers also used their financial capital and class privilege to support the schools. This strategy of using class privilege to organize the schools greatly influenced the schools’ operation and access. Conversely, students with disabilities who did not have access to the schools were those living in rural areas of the island and did not have the financial means to attend school. Here, even
segregation occurred for disabled students among their peers due to poverty. Thus, the intertwined configurations of education access, disability, and poverty are instrumental to school access and organizing. The intersectional approach of influencing others in the government system, church groups, and local communities to think about the inequalities in excluding students with disabilities in schools was a great strategy that the organizers employed. The women organizers used their privileges, community status, and networks to seek financial support from overseas organizations that supported disabled people. This was a crafty move by the women organizers because it led to the global awareness of what was happening in the Samoan disability community. More aptly, the Samoan government was eventually “forced” to acknowledge and act on changing formal policies regarding disabled students in schools.

**Paradoxes and Constraints of Community Activism**

International aid supported the establishment of schools for students with intellectual and physical disabilities. Despite, these generous funding sources, the schools generally struggled with sustaining its operational costs and paying staff since these monies did not arrive on a consistent basis. Throughout the study, the women organizers were clear in their stories about the struggles of obtaining funding to maintain the schools and getting institutional support from government organizations. This study is also about the struggle of constructing educational institutions for the disability community and the manner in which these commitments have evolved. The unfortunate results of limited funding, then, influence the sustainability of the schools, but more importantly, the academic progress of the students. As the women organizers shared, staff turnover in the schools was an ongoing problem because it disrupted the students’ academic progress and school operations. Thus, if the schools did not have sufficient funding to
pay their staff members, they often left to find other jobs. In the end, the students were the ones to lose out from such constraints.

The irony of Aoga Fiamalamalamalama and Loto Taumafai was that the schools physical locations led to separate education facilities and interactions between disabled and non-disabled students. Thus, the idea of school inclusion was not a continuum and some students with disabilities only attended the studied schools, while a few students, like Lisa, attended government school. In other words, non-disabled students were rarely around students with disabilities, and the precarious question of inclusion is a consequence of separate education facilities. More aptly, attitudinal and systemic inclusion in schools was a factor that seldom changed, even with the physical establishment of schools’ for students with disabilities.

**Social and Power Relations**

Samoa’s economic status as a developing country contributed to the financial difficulties that the education system encountered. The larger educational structures were not in place and this led to limited financial resources and services. The minimum resources such as trained staff, school campuses, and government support are a few examples of the dynamics that influenced the power and social relations in the Samoan context. Social and personal factors also influenced the women organizers participation in the disability community. For example, many of the women were parents with disabled children. The women organizers’ personal relations to disability coupled with Christian values and charity drove their advocacy. More importantly, most of the women organizers were educated outside of Samoa, and I think this factor played a significant role in how the women understood the rights of people with disabilities, strategically collaborated with community allies, and asserted their agency in making collective changes
throughout the community. These dynamics greatly affected how the women organizers understood disability.

Because Samoa is a predominantly Christian society, the churches also influenced the advocacy work that the women organizers carried out. For instance, the faletua (pastor’s wives) supported the preschool movement and this led to the establishment of preschools in several villages. The faletua helped with hosting the preschools in church halls and teaching the students, as most of them were trained teachers. The interesting factor of working with the women organizers was their wavering beliefs about the causes of disabilities. Most of the women organizers subscribed to the medical model approach. Some of them endorsed indigenous approaches to disabilities, while some valued the spiritual and religious explanations of disabilities. Some women organizers endorsed all these understandings of disability and sickness. This example also reminded me that in community organizing and social movements, there are varying consensuses on how people accomplish tasks, as their beliefs, agendas and motivations are diverse. Finally, the women organizers’ efforts were not an isolated incident. At the time, the disability rights movements were also happening around the world in Britain, Canada, Mexico, and the U.S. (Ingstad & Whyte, 1999). Another interesting factor was the women’s tensions in their advocacy work and personal preferences. Some of the silences, pauses, and changing of the topics were observed when discussing conflicts they encountered among themselves and with other NGOs.

**Situating NGOs in the Broader Education Institutions**

The norm in the 1970s was that people with disabilities did not attend formal school. In 1979, this way of educating students changed when schools like Fiamalamalama and Loto Taumafai were established. The new approach shifted the student demographics to include
students with disabilities. However, this change only meant that students with disabilities were only physically in formal schools. Fiamalamalama and Loto Taumafai were separate from the government schools, in physical location and school student attendance, which continued to foster the exclusion of students with disabilities from their non-disabled peers. The organizing of the schools by the women organizers endorsed the presence of students with disabilities and the “labor of love” that transformed the inclusion practices of people with disabilities and other marginalized communities on island. The Samoan education system changed its exclusion of students with disabilities, poor students, and preschoolers by force. The ableist views inherent in the education system favored only “certain” kinds of students to be educated, an inaccurate assumption.

The trajectory of people with disabilities involved in the education in Samoa finally came to fruition in the 1980s. Students of Aoga Fiamalamalama seldom attended any other school. In Loto Taumafai, some students attended government schools, but some did not. Given the circumstances at the time of a newly independent and developing state that was minimally invested in the education system, the women organizers did the best they could with the limited resources they had. The organizers made a conscious choice to establish the schools and to provide an education for people with disabilities. In many ways, their efforts laid the groundwork for families to continue to push for--more expansive educational opportunities, including more inclusive placements and access in government schools.

My goal here is not to lessen or diminish the efforts of the women: establishing the two schools was a much-needed task at the time. My point, instead, is to acknowledge some of the unanticipated results of the organizers well-meaning efforts. While the women organizers’ efforts deserve accolades and a place in history, as the saying goes, there are also multiple
interpretations to a story. One interpretation recognizes the unintended part of the story of advocacy and inclusion: that is the issue of continued exclusion from age-like peers in inclusive classrooms and schools. Recognizing these shortcomings, the women organizers nevertheless remain hopeful for more opportunities to come for the disability community. This story also teaches us that reforms and reformers of schools in one era, while worthy of respect and honors, often become the entrenched institutions that needed a challenge in another time. As Sina suggested:

We honestly did not know what the outcome of our school organizing would be.

We did not have long-term goals for the school. Honestly, we weren’t sure if the school was going to work out. We are excited that the schools are still open today. (Personal communication, October 13, 2013)

Sina touches on the reality of NGOs, and that is many do not survive because of the inconsistencies of funding, staff, and commitment. In addition, the aid relationship between donors and NGOs tend to conceptualize development intervention as an uncomplicated and harmonious process based on mutual goals and interests (Baaz, 2005). Criticism of this model of aid development comes from not accounting for perceptions of power and disembodied social categories or as passive recipients of development intervention (Foucault, 1980). Yet, these barriers of striving for equal partnerships are the bigger pictures that the women organizers share in hopes that others would find their stories useful. This story can also inspire other school reformers and advocates to consider what is valuable and needed, in order to create educational systems for all students.

The main point here is that the women organizers, many of whom were also members of the disability community, parents, or allies, made the choice to start a school for their
community. This decision is what ultimately interested me in this history. They created schools in spite of a sordid history of state schools, asylums, and institutions that fostered the idea that such institutions would rehabilitate individuals with disabilities and ready them for community life, but instead became dehumanizing warehouses for people. The genealogies of these large state run institutions often linked to ableist and racist government mandates or policies; unlike the schools in this study, they were not started due to government mandates but to community needs. Top-down policies and mandates, as many state-sponsored schools and programs, often did not include people with disabilities, families, or community allies in the decision-making and organizing processes. Conversely, organizations of the schools featured in this study were by grassroots efforts with minimal government involvement. Such dynamics greatly changed the power relationships of the schools to the students and the community. Moreover, the community’s investment in these schools often superseded community involvement even in the government schools. Although segregated, these schools differed in important ways from other segregated state run institutions for the disabled.

The move away from dependence on state guardianship and authority was a key motivation of the deinstitutionalization movement in the US that took place around the mid-60s (Taylor, 2009). Before this movement, the government often had a “strong-arm” approach to overriding the rights and best interests in the lives of people with disabilities. Contrary to this history, the establishment of the two schools in Samoa for people with disabilities was an intentional decision by the disability community and their allies. In fact, the local government’s involvement in creating and sustaining these schools was minimal. Therefore, the vibrancy and drive to keep these programs going for future generations came from a position of advocacy and choice to make conscious decisions that meet the needs of a group (which over time changes).
The indigenous valuing of collective needs and community solidarity shines through this history. More importantly, the most intimately effected groups by the organizing were actively involved in these programs. The women organizers, I contend, modeled a powerful example of grassroots efforts that were empowering and sustaining. Namely, the women were also successful in the cultural aspect of advocacy by respecting traditional Samoan protocols, while also politely resisting these values of women’s roles and citizenship. The more notable part about the women organizers’ advocacy was their ability to balance cultural and social protocols in building coalitions. Due to Samoan traditional systems, the women have very specific roles and responsibilities within the home and community spaces. However, the women organizers were not controlled by these heteronormative ideas and they worked together to expose the discrepancies in the educational systems and cultural practices.

Summary of Key Findings

In this dissertation, I argue that organizing these schools was an example of resistance to ableist and normative structures that excluded people with disabilities. The schools started with two major tasks of locating funding and land to establish them. Finding monies to establish the schools led the women organizers to ask the local government for support, without much luck from the government, the women organizers turned to applying for grants from organizations abroad, and gathering support from community allies. Receiving international aid from countries such as New Zealand, Australia, Japan, US and Canada were fundamental to the founding of the schools. IHC in New Zealand led the way in making this goal a reality. Finding land space to relocate the schools was another difficult task. The schools eventually received land: the preschool advocates received three and a quarter acres of seawater swampland from the local government; Aoga Fiamalamalamala eventually bought free hold land after encountering
difficulties with government organizations and other NGOs; and Loto Taumafai was relocated across the street from the local hospital on government land.

In term of needs, support was not limited to financial support; it also extended to what Lupe, Fiamalamalama organizer explained, “about changing negative attitudes and beliefs about disabled people.” (Personal communication, January 7, 2013) Establishing Fiamalamalama and Loto Taumafai was a collective effort that was “a lot of work and fun”, something that the women in this project want people to know. However, in this case, the women organizers voluntarily planned the schools with their allies and asserted their power in making decisions and goals they endorsed. Specifically, women with disabilities were active organizers in these schools and that is a rare case, because historically, most of them are the pitied inhabitants of such facilities.

As I argue throughout the dissertation, these organizing logics and practices changed the ableist structures within the community, especially in the educational realm. The difficult lesson here is to analyze how these aspects are constantly evolving and how to adapt them to the needs of the time. The women organizers’ politics of inclusion and alofa (love) also reminded the broader Samoan community about tautua (service) and the community’s inclusiveness responsibility to all her citizens. The women organizers embodied cultural norms such as harmony, peace, respect, love, and reciprocity that comprise Fa’a Samoa (Samoan way of life). The organizers’ resistance to the cultural rules was remarkable to observe because not only did they respectfully resist the norms of women’s roles and mothering, but they also pushed the boundaries of belonging. Hence, the women organizers resisted ableist attitudes that devalued differences by equating able-bodiness as the standard of humanness and acceptance (Siebers, 2008). Throughout the women’s organizing efforts, ableist attitudes embedded in the structures
and systems they tried to disrupt. For instance, schools and the inclusion of disabled students, finding financial support from the local government agencies, and changing attitudes of people in power about disability issues.

Sasha’s and Lisa’s experiences as former students of the schools cannot be underestimated. Their stories, as two women with disabilities, spoke to multiple complexities regarding disability, gender, culture, and inclusion. Sasha and Lisa refuse to fit into neat labling by ableist categories or accept the idea that they are limited to the category of women with disabilities. As their stories conveyed, they also occupied various roles in the community that challenged ableist structures about being a mother, aunt, sister, and advocate. More aptly, Sasha and Lisa spoke to the adverse experiences they encountered in the community, their struggles to attend schools, and how they coped and resisted by immersing themselves as advocates and proponents for the disability community. The broader implications of their stories are the purposeful interruptions of an exclusive discourse that viewed people with disabilities as less than or weak, despite the cultural principles of alofa and inclusiveness.

Weaving Together the Larger Implications

It is no surprise that educational curricula, policies, and activities emerged from and continue to uphold Eurocentric values and ideologies. This tends to minimize and erase the knowledge experiences, and values of those who do not have positions of power (Tuck, 2009). More importantly, Maldonaldo-Torres’ (2011) conceptualization of thinking through decolonial turn is critical in understanding the double reach of colonial legacies in education, especially the deep inequities tied to the history of Samoan families in schools. Thinking about decolonial turn also forces us to trace and employ distinct expressions across established bodies of knowledge. Thus, without a critical examination of how ableism and racial classification operates in our
education system, we risk justifying a history of exclusion of people with disabilities in schools. Since, ableism does not exist only in the bodies of the people oppressed by it, but also is an issue of concern for all of us who are dedicated to social change, inclusive communities, and education as a liberating tool. A fascinating realization from this project is the fluid ways that people with disabilities were included and excluded in the wider Samoan community. For instance, in the home sphere, people with disabilities were included, in the Christian church realm, some people with disabilities were leaders, but excluded from formal schools until the 1980s. Thereby, it is difficult to assert a clear trajectory of exclusion and inclusion. What is constant is the idea that dismantling and decolonizing ableist systems is not possible without recognizing and relinquishing able-bodied privilege.

Parent advocacy on behalf of children with disabilities has never been about getting ahead of other students by asking for exceptional privileges. For the most part, it is about parents and caregivers wanting the best for their child in school. Historically in schools, educational policies and reforms did not change because the schools realized the inequities; the burden of inclusion and equality often fell on students’ families to ensure the honoring of their rights. Despite these pushes and pulls in the schools’ organization, the struggle to articulate and promote values of inclusiveness in an environment that purports inclusion and fairness are lessons that the Samoan community can improve upon.

This project was not limited to the spheres of educated women organizers and advocates; it was also about acknowledging the gender imbalances in positions of leadership that were inaccessible to women but often occupied by men. The educational “inclusion” of disabled students in schools was not a clear course. Here I mean, the women organizers were successful in shaping the schools for disabled students, but the inadvertent outcome of these approaches
reinforced the exclusion of students with disabilities from their non-disabled peers. In other words, by creating these schools, the government schools retained the status quo of exclusion. The government schools are off the hook about having policies and services that include students with disabilities. More aptly, the general education settings continue to operate in the status quo and students with disabilities are still an invisible and excluded group in schools. This was not a goal in the women organizers agenda, but unfortunately an inherent consequence. This is an important lesson for school reformers to consider in the future.

As Lupe related, “There was a need and this is what we did.” (personal communication, January 7, 2013) Lupe’s comment reflects the pressing need at the time for educational inclusion. Unfortunately, in retrospect the women organizers had to make tough choices throughout the establishment of the schools. Specifically, I argue that the government schools would not have embraced students with disabilities, if the women organizers had not acted to change these practices. Their efforts are applauded. If anything, this study probes us to weigh the benefits of parental advocacy against the unwieldiness of exclusive policies and ideologies of belonging.

The women organizers were also perpetual advocates because they did not just rally for the disability community--they also supported the difficulties faced by the preschool movement, education funding, and recognizing the relevance of solidarity politics in transforming oppressive systems. However, as this study shows there is a need for more efforts to include poor students living in rural areas. The women organizers commitment is reflective in our conversations; when I interviewed the women organizers many of them verbalized that they have scaled back on their involvement in the schools and they trust the current staff to carry on the “torch”. However, as I prodded them to share their thoughts about the current happening in the schools,
many of the founders were up to date with the schools’ matters. Hence, I feel that the women continue their activism regardless of their physical location to the schools. For example, Sina continues to attend and give talks in the community about issues affecting the disability community. Lupe, Fili, and Sisi are still affiliated with the schools in terms of fundraising, giving gifts, and helping with the school budget, despite their claims of distance.

**Researcher Implications.**

As a researcher, this project was possible because of my familial connections to the women organizers. Without this factor, my research project would have taken much longer to complete because I would have first had to build trusting relationships. Even though, I felt like an insider in this project, there were areas of tension in my study that I was not privy to or allowed to engage, for instance, the personal conflicts among some of the women and the discussion around “thieving” of the monies among NGOs. From this research project, I learned that research takes time and I have to be patient and trust the long process of doing research. One of my fears in conducting this research was about how I would appropriately represent the participants and their stories. I think I alleviated these anxieties when I started working with the women and I was forced to always be transparent about my research goals and methods. The women organizers intimate involvement (reading drafts, editing interview transcripts) in this project helped me to feel more at ease. More importantly, I learned that there are multiple versions of the stories about Aoga Fiamalamalama and Loto Taumafai; this is one version.

I was ambivalent about celebrating the establishment of the schools as they promoted the inclusion of students with disabilities in the Samoan education system but also reinforced their segregation from non-disabled peers. My concerns about commemorating the organizing of the schools also linked to the undercurrents that celebrating such schools would potentially end the
discussion of including students with disabilities in schools. Hence, I was conscious that the implications of this study could also influence future conversations about membership in communities and government responsibilities to all students.

The stories in this study were filled with tensions and challenges about advocacy, inclusion, and/or access to schools. Tensions about medical and social models of disability were apparent in how the students required medical services while also resisting dominant views that their bodies are “broken” and need “fixing”. Yet, the students with disabilities continued to seek quality healthcare to improve their quality of life. The use of class privilege to organize the schools was a stark reminder of who can accomplish such tasks. Moreover, this task of school organizing also speaks to the upper-middle class privileges of the women organizers and former students. This factor also reminded us of who can access these services and schools and who cannot. For the cases of Aoga Fiamalamalama and Loto Taumafai, students with the financial resources were the benefactors of the schools, while leaving out poor students. The longstanding tension of exclusion people with disabilities in society suggests that much work still necessary and a call for action to address these inequities continue to motivate future studies. Using storytelling as a tool to gather data and decipher distinctive meanings in my participants’ narratives, while the use of grounded theory and ethnographic methods prompted the recognition of codes and themes. The capturing of what my participants shared in common in their stories was a difficult task to track in my approaches to data analysis. Thus, using my archival data and follow-up interviews were some strategies used to reconcile these tensions. Clearly, my position as an insider within the researched community was also limited and I continue to create opportunities for conversations with the participants in this study. In addressing the broader structural inequities inherent in this study, the lessons taught from this study helps us to identify
colonial and indigenous pasts and presents and how Samoan Christian values of love and belonging continue to contradict exclusive educational policies and attitudes. The naming of such tensions is essential for change and providing insights into how future transformations can be sustainable.

Implications of the Study

Findings from this research also shed light on the limited services and programs that support indigenous women with disabilities. Even though these schools afforded women with disabilities with a primary education, the reality is that after this phase of their lives most of the women were unemployed and isolated from the community. The need for further research projects exist in the areas of transition to employment skills, vocational education, and reproductive rights. As Sasha’s and Lisa’s experiences revealed, they were atypical students who received an education compared to their peers. Both women are grateful to their parents and families for their support. Leadership roles in the community are vital to conveying the needs and collective agendas that the disability community faces daily. As this study showed, colonial structures and normative systems do not change on their own and the advocacy led by communities deeply affected by these social organizations that prompted change.

It is necessary for more research and resources in the areas of transitional options for people with disabilities after K-12 grades. The limited schooling options for adults with disabilities required fundamental changes in services and policies to allow for meaningful life choices. This study also reminds us of the limitations of the charity, medical and social models of disability. Here, the well-meaning intentions at the time but sometimes-distressing implications those future generations have to dismantle and reform. In doing advocacy work, a grounding model approach to this work involves a committed group with similar goals and
objectives. The women organizers learned early on that they needed to gather support from already established organizations with similar missions. IHC in New Zealand was this organization and this led to a long time partnership between the organizations.

**Future Research**

Further research must continue in addressing the quality of life for women with disabilities, especially in the global South region. For instance, there is a need for more studies in the areas of employment opportunities, vocation programs, reproductive rights, and support services that will alleviate poverty, isolation, and abuse in the disability community. In addition, this study hopes to extend its purview to include more views about the schools by former students and their families. Moreover, further conversations with the women organizers allies such as the faletua (pastor’s wives) are other relevant perspectives that would clarify the struggles and tensions that the school founders and students faced during this trying time of transformation. Finally, a message that I hope is taken away from this study is something that Lisa, a former member of Loto Taumafai reminded me about, “The disability advocacy work I do, is for everyone”. More action and research in our communities must reflect these collective values.
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Appendix A

Interview Guides

Semi-Structured Interview Guide: Teachers and Local School Personnel

1. Can you give me basic background information about yourself? What is your job, how long have you been working in this school? And how long have you been working in the field of education?

2. How did you become involved with the Aoga Fiamalamalama and Loto Taumafai School in the 1970-80s?

3. Can you explain what was happening in schools at the time?

4. What led you to become involved with the school?

5. What was the impetus of the school and why was the school started?

6. What are some changes in the educational system since you started teaching or working with Aoga Fiamalamalama and Loto Taumafai School?

7. What changes have you experienced since you began working for the school? Why do you think these changes have occurred?

8. How do you feel students with disabilities have been affected by these changes? Can you share any examples?

9. What kinds of activities occurred in the classrooms? At parent meetings? On field trips? How many students and parents participated in these activities?

10. How did the administrators and teachers organize and plan school activities? What was their curriculum?

11. What problems occurred during the course of the curriculum’s implementation?

12. What does disability mean?
13. What do you believe causes disability?

14. Where do you think these beliefs come from?

15. Do these beliefs change with different disabilities?

Semi-Structured Interview Guide: Parents and Community Members

1. Can you give me basic background information about yourself; what is your job, How long have you been affiliated with Aoga Fiamalamalama and Loto Taumafai School? How long have you been affiliated with the disability community?

2. How did you become involved with the Aoga Fiamalamalama and Loto Taumafai School in the 1970-80s?

3. Can you talk more about why the school was started and what were some factors that led to this point?

4. Can you explain what was happening in Samoa at the time?

5. What are some changes in the educational system since you attended/worked with Aoga Fiamalamalama and/or Loto Taumafai School?

6. How did you become interested in organizing the schools for people with disabilities?

7. What does the word disability mean?

8. What do you believe causes disabilities?

9. Where do you think these beliefs come from?

10. Do these beliefs change with different disabilities? How did you organize and get people to become involved in the starting of Aoga Fiamalamalama and Loto Taumafai?

11. What did the parents and community members do to raise money for the schools?

12. What aspects of community organizing were difficult and/or rewarding?

13. What were some missions and goals that influenced how the schools would be organized?
14. What were some challenges and benefits of starting Aoga Fiamalamalama and Loto Taumafai Schools?

15. What advice do you have for policy makers about schooling for students with disabilities?

**Semi-Structured Interview Guide: Former Students**

1. What year did you start attending Aoga Fiamalamalama and/or Loto Taumafai School?

2. How did you come to attend Aoga Fiamalamalama and/or Loto Taumafai School?

3. During the 1970-1980s, were you attending any other school in your community?

4. What were your experiences as a former student at Aoga Fiamalamalama and/or Loto Taumafai School?

5. What do you remember the most about the school?

6. What did you do after school?

7. What activities were you involved in after school?

8. What nicknames did you family call you growing up? How about your friends?

9. How would you describe the school to other students who do not know about Loto Taumafai?

10. What does the word disability mean? What do you believe causes disabilities?

11. Where do you think these beliefs come from? Do these beliefs change with different disabilities?
12. What role did your family play in organizing the school?

13. What role did your parents or elders play in helping you attend this school?

14. What role did your church community play in your education?

15. How would you describe Aoga Fiamalamalama and Loto Taumafai School to people who do not know about it?

1. How would you describe your overall job, and how long have you been doing this particular job? What other jobs in the field of education did you have prior to this position?

2. What changes have you witnessed in the field of education since you have been involved, and what have been major reasons why you think these changes have occurred? [Focus on Samoa and international changes]

3. What role do you have in your position to shape some of the changes that have been made? In what ways do you have control over creating or shaping standards based on reform efforts? What is your role to help implement such reforms?

4. How do you see the policies and reform efforts effecting students with disabilities? Do you have any particular examples?
   
   a. How do testing practices affect students with disabilities?
   b. How do you think movement to charter schools affect students with disabilities?
   c. How do you think “highly qualified” teacher requirements affect the changes?

5. When discussing curriculum with school officials, how do students with disabilities come into play concerning decision-making?

6. How do political ambitions, university research, or other entities influence how policies are shaped?

7. How many students were enrolled in segregated schools or non-government organizations during the 1970-80s? How were they selected? What were their characteristics and backgrounds?
8. What policies or practices are the most important for students with disabilities? Why? How can schools or the community strive to accomplish these goals?

9. What does the word disability mean?

10. What do you believe causes disabilities?

11. Where do you think these beliefs come from?

12. Do these beliefs of disability change with different disabilities?
Appendix B

Consent Form

Trying Times: Disability, Activism, and Education in Samoa, 1970-1980

My name is Juliann Anesi, and I am a doctoral student in Special Education at Syracuse University (New York, USA). I am inviting you to participate in a research study in order to complete my dissertation. Involvement in the study is voluntary, so you may choose to participate or not. This sheet will explain the study to you and please feel free to ask questions about the research if you have any. I will be happy to explain anything in detail if you wish.

I am interested in learning about your perspective on the ways that Aoga Fiamalamalama and Loto Taumafai Schools have impacted the education of people with disabilities in Samoa. Interviews will occur with individuals who were affiliated with the school during the time of 1970-1980. You will be asked to participate in an interview with the researcher in a locale of your choice.

This interview will take approximately 1-2 hours of your time. All information will be kept confidential and will be locked in the home of Juliann Anesi. I will assign a number to your responses, and only I (Juliann Anesi) will have the code to indicate which number belongs to which participant.

In any articles I write or any presentations that I make, I will use a made-up name for you, and I will change details about where you work, and the exact title of your job.

It will also be requested of you that I audiotape the interview. The audio content will be recorded in digital form and Juliann Anesi will transcribe each interview. The audio file and transcriptions will be deleted two years after the study is completed, and then disposed of, unless otherwise requested by the participant to donate to a research center or educational archive. During the study, the recordings will be held in a secure location and transcriptions will be protected by passwords on the researcher’s personal computer. The audiotapes will only be used for data analysis, and will not be played or used in any other venue.

The benefit of this research is that you will be helping me to understand more deeply how one group of disability allies, parent advocates, students, teachers, and women organizers created the Aoga Fiamalamalama and Loto Taumafai Schools for the disabled people in Samoa. This information should help me to offer specific educational and policy recommendations about how activism, disability, and inclusion are understood in Samoa. As changes are constantly being made in the realm of disability national policy, global awareness on disability rights (e.g. UN Convention on the Rights of People with Disabilities), and educational policies to include all students in government schools, this is particularly a viable topic at the present time. By taking
part in this research, you will experience the benefit of sharing your story about how you view
the reform efforts and future changes.

The risks to you of participating in this study include the possibility of emotional reactions
during interviews. These risks will be minimized by allowing the participant to determine the
depth, length, and locale of the interview. You may also be concerned that there is a risk that
your identity might be revealed if you partake in this interview. In order to assure your
confidentiality I will change your name, and will attach a vague job title to you, and/or personal
characteristics such as village names.

If you do not want to take part, you have the right to refuse to take part, without penalty. If you
decide to take part and later no longer wish to continue, you have the right to withdraw from the
study at any time, without penalty.

If you have any questions, concerns, complaints about the research, contact Juliann Anesi at
jtanesi@syr.edu, or at 310-251-3221, or my university advisor, Professor Beth Ferri, at
baferr@syr.edu.

If you have further questions about your rights as a research participant, or if you have questions,
concerns, or complaints that you wish to address to someone other than the investigator (Juliann
Anesi), please contact the Syracuse University Institutional Review Board at 315-443-3013.

All of my questions have been answered, I am over the age of 18 and I wish to participate in this
research study. I have received a copy of this consent form.

For an Interview:

☐ I agree to be audiotaped for an interview

☐ I do not agree to be audiotaped for an interview

All information collected will be held as confidential data.

_________________________________________  ________________
Signature of participant                         Date

_________________________________________
Printed name of participant

_________________________________________  ________________
Signature of researcher                          Date

_________________________________________
Printed name of researcher

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Appendix C

List of Abbreviations

APAC  Asia Pacific Action Committee
IHC   Intellectually Handicapped Inc. Centre
JICA  Japanese International Cooperation Agency
LMS   London Missionary Society, or LAMOSA
MWCSD Ministry of Women, Communities and Social Development
MESC  Ministry of Education, Sports and Culture
NOLA  Nuanua O Le Alofa
NUS   National University of Samoa
SENSE Special Needs Education Society
WSTEC Western Samoa Trust Estate Corporation
## Appendix D

Glossary of Samoan Word and Map of Samoa

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Appendix E

Map of the Samoan Islands

Curriculum Vitae

Name of author: Juliann T. Anesi

Place of birth: Samoa

Date of birth: May 7, 1976

Education:

2015 Ph.D. in Special Education, Expected December 2015 Syracuse University
2010 Certificate of Advanced Studies in Women and Gender Studies, Syracuse University
2008 Certificate of Advanced Studies in Disability Studies, Syracuse University
2005 Masters of Science in Special Education, University of Hawai´i at Manoa
1999 Bachelor of Arts in Communicative Disorders, California State University Fullerton

Publications:

Professional Experience:

2010-2012 Graduate Research Assistant (GA), Native Student Program Office of Multicultural Affairs, Syracuse University

2009-2010 Teaching Assistant (TA) Inclusive Education Undergraduate Teachers Program; “SPE 346 Methods & Curriculum in Severe Disabilities” by Dr. Julie Causton, Syracuse University

2008-2009 Teaching Assistant (TA) Inclusive Education Undergraduate Teachers Program; “EDU 203 The Study of Elementary and Special Education Teaching” by Dr. Christy Ashby, Syracuse University

Awards and Honors:

2014 Marsha Smith-Lewis Dissertation Fellowship, Syracuse University

2009-2012 Graduate Scholar Leadership Grant, Syracuse University

2007-2008 Graduate Scholar Honor Scholarship, School of Education, Syracuse