

**Unveiling (In)equality in resources for Children with Intellectual and
Developmental Disabilities: Three Chinese American Caregivers' Experiences**

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May 06, 2020

Abstract

Throughout American history, disability has been utilized by the American government to justify and legitimize policies as methods of oppression against immigrants, women, and people of color (Baynton 2005). Through the establishment of the Americans with Disabilities Act, all Americans with disabilities should have the same access to quality care and resources that are appropriated to their individual needs (Weber 2010; Connor and Ferri 2013). Current literature on caregiver's experiences raising children with intellectual and developmental disabilities (IDD) are predominantly focused on white middle-class families (Zechella and Raval 2016) and are thus not representative of the experiences of caregivers in minority communities. Disabilities and mental health are two stigmatized topics in the Chinese American communities. The needs and experiences of minorities like Chinese American immigrant caregivers differ from White middle-class families. Through two models of disability, social and medical, this thesis aims to understand how the intersectionality of their marginalized identities as Chinese American immigrant caregivers impacts their understanding of their child's IDD, and their experiences navigating the health, social and education institutions to access necessary resources for their child's care. I conducted semi-structured interviews with 3 Chinese American caregivers who cared for children with IDD in English and Mandarin. These interviews revealed the disparities in both quality and access to resources; the stress and initial reactions that caregivers had to the child's medical diagnosis; the multitude of barriers including linguistic, structural, racial, socioeconomic and the cultural insensitivities from professionals' that caregivers endured; and the support groups that caregivers relied on. The three Chinese American caregivers emphasized the need for systemic and social change to ensure that the professionals that work with families like theirs are well-trained, committed, culturally competent, empathetic, and equipped to provide comprehensive language services. It is through these changes that it can bridge the disparities in access and quality of care for children with IDD in families like theirs.

Acknowledgement

I want to thank my thesis advisor Professor Shani Evans for her constant guidance and patience, especially when I needed the most. I want to also thank Professor Farha Ghannam for her constant support and extending her arm to me (on multiple occasions) during my times of distress. I thank my Writing Associate Mentor Alexis Riddick for having the patience and compassion to always be there to support me and be my cheerleader when I felt so drained and stressed out. A big thank you to Dr. Michael Stillman, Dr. Wendy Ross, and Dr. Mary Stephens of Jefferson Health (SKMC) and Jefferson Center for Neurodiversity for providing me with unlimited attention and encouragement throughout this project. I also want to thank Professor Chih-Jen Lee from the Chinese Department at the University of Pennsylvania for taking time out of your busy schedule on multiple occasions to guide me through translating the interview guide. Thank you to all of my apartment mates and friends who have been there to push me through the multiple times I needed to rewrite, that I didn't think that I was going to be able to finish, and ensured that I have the capability to finish this (Especially Sofia Cabrera'20, Alliyah Lusuegro '20, Elena Do'20 and Joshua Chan). Lastly, I want to thank every reference and participant for being so willing to share your life, your stories, and experiences with me. I appreciate your vulnerability, your patience in working with me. This paper would not have been completed without your contribution.

Table of Contents

<i>Abstract</i>	2
<i>Acknowledgement</i>	3
Disability Statistics.....	12
History of Disability Rights Movement.....	12
Models of Disability.....	21
Ab/normality.....	21
The Medical Model of Disability:.....	22
The Social Model of Disability.....	24
(Biomedical) Diagnosis, Treatments, and Resources for individuals with IDD.....	31
Barriers to Care.....	40
Addressing Barriers.....	43
Intersectionality of identities.....	46
<i>Methodology</i>	48
Justification for the study:.....	48
Positionality:.....	49
Sampling.....	52
<i>Steve</i> :.....	53
<i>Linda</i> :.....	54
<i>Michelle</i>	55
Data Collection:.....	56
Data Analysis:.....	57
<i>Analysis</i> :.....	59
The Stress and Reactions of Medical Diagnosis.....	62
Parental Experiences Navigating Resources.....	67
Linguistic Barrier.....	69
Culturally (in)Sensitivity.....	74
Structural Barriers.....	79
Racial/Socioeconomic Barriers:.....	83
Support Systems.....	86
<i>Conclusion</i>	90
<i>Limitations</i>	97
<i>Key Terms</i>	98
<i>Appendix: Interview Guide</i>	99
<i>Work Cited</i>	104

Introduction

Disability. When we think of the word disability, our minds often directly link disabilities to the disabilities that are visibly seen. Those who have physical mobility disabilities like amputees or those with congenital conditions. Throughout my public-school years, whenever I heard the words special education, I always associated it with someone who has special needs and lower intelligence quotient (IQ) than a typically developing student. In a public school of 6,000 teenagers in New York City, there were many with undetected disabilities that were unaccommodated for. I have always attended public schools where the school demographic were predominantly immigrant/first-generation immigrants, more specifically, Asian immigrants. In college, the meaning of the term ‘disability’ expanded for me. I discovered that we have a student disability services office in the office of academic success. I also came to learn that students at this elite institution were getting accommodations like extended testing time, computer access during class, and other accommodations I never even knew existed. It was at Swarthmore where I learned about the prevalence of Attention Deficit Hyperactivity Disorder (ADHD), dyslexia, and other learning disabilities among the student population. As an immigrant child who came from a public school, I had only been surrounded by ‘typically developing peers’, or so I thought.

As an Asian American who grew up in a predominantly Chinese immigrant neighborhood in New York City, disability and poor mental health are stigmatized topics that were often neglected by our community. Mental health conditions were often seen as a sign of weakness; they are just in our heads. They are a potential cause that may ruin the family’s reputation. Likewise, disability is seen as a sign of weakness and a liability to their family. As such, it was difficult for me to have conversations with my family about the state of my mental

health and my need for treatment. They were quick to dismiss that it was all in my head – that as long as I change my way of thinking, everything will be fine. Invisible conditions like mine are considered to be self-inflicted and temporary in my family. My experience is not unique to me. I have had extensive conversations with my friends in my community, many of whom have struggled through similar experiences navigating conversations about mental health with their families.

Individuals with ab/normal mental conditions and disabilities are often judged and shamed by many in my community. It is normal to use derogatory terms like 疯子 *feng zi*, 傻子 *sha zi*, 残废 *can fei*, which means “maniac”, “idiot”, and “crippled and useless” respectively (Hallet 2005). Thus, it did not surprise me that in the fifteen years that I have lived in multiple Asian American neighborhoods of NYC, I rarely saw individuals with apparent physical disabilities on the streets, nor individuals with apparent intellectual or developmental disabilities. Family members often kept individuals with disabilities at home. I attempted to search for culturally and linguistically competent mental health resources as well as disability-related resources in my neighborhood with very limited success.

What is not seen, is not “there”; What is not there, is not an issue.

This made me question; what about those whose conditions are not physically apparent? What about those who are medically diagnosed with an intellectual/developmental disability? What are their experiences like growing up in an Asian American household? How did their caregivers perceive their condition? What are the caregivers’ experiences raising a child who is dis/abled? Few studies on caregiving and disability focus on the intersectionality of multiple identities and factors that impact one’s perception and experience with intellectual and developmental disabilities (IDD). There is especially little research on Asian American

caregivers for individuals with IDD. Most studies about the experiences with American parents with children with IDD are primarily centered around White middle-class families (Zechella and Raval 2016). Such studies are thus not representative of the collective experiences of all caregivers with children with IDD. Although in theory, disability laws have been established so that anyone diagnosed with a disability, may have access to the resources provided by the government, racism and ableism persist against Asian Americans such that the discrimination they face devises additional barriers and inequalities for those who already experience multiple forms of marginalization within their communities (Frederick and Shifrer 2019).

This paper will begin with the history behind disabilities and the disability rights movement. Disabilities have always been used as a relevant marker to define hierarchal relationships and to justify inequality throughout history. Throughout the era of women suffrage, civil rights movement, and immigration restriction legislations, disability was deeply intertwined with these hot topics of debate (Baynton 2005). Disabled individuals, people of color, women, and immigrants were all considered minorities. Disability functioned for these folks as a justification for their inferior status in American society. During the end of the nineteenth century, the early twentieth century, the American government utilized disabilities, physical, mental and emotional, to form immigration policies that crafted an image of the undesirable immigrant (Baynton 2005). The immigration policies judged immigrants on their fitness to contribute to American society. Thus, those who were deemed imbeciles, feeble-minded or blind, often from specific ethnic groups, were deemed unfit and were denied access to citizenship based on their potential on becoming a public charge (Baynton 2005). Disability was used in American history as a method of oppression.

Ethnicity, immigrant status, and disability thus all intersect in the concepts of normality and legitimacy. These two concepts were used to justify the denial of legitimacy to rights for certain groups of individuals including women and Black folks. They are also utilized to establish the social hierarchy which continues to persist today (Baynton 2005). In the study and practice of eugenics in the 1900s, normality was understood as the western notion of progress. Those who were nonwhite and those who were disabled were connected because they were both depicted as evolutionarily laggard, unlike white folks. Disability here is synonymous with abnormality (Baynton 2005).

The paper then shifts to define normality within the context of disability. The cultural meaning of normal is constructed in tandem with the concept of disability. What and who deviated from the assumed norm is considered defective, below average. Since the late twentieth century, medicine, pharmaceutical companies, governments, advertising & media companies, and biotech firms became huge influential factors in medicalizing aspects of our daily lives including birth, death, and menopause, to determine health (Lock 2004; Zola 1976). The normalization and medicalization of everyday behaviors and conditions constructed a medium in which if one's condition deviated from the biomedical understanding, they are labeled as abnormal (Lock 2004). With health professionals being the agent of social control, they inevitably have the power to determine what health conditions and symptoms can be medicalized and diagnosed. Medicalization is a powerful force in defining one's disability (Conrad 2007).

The two main models of disability discussed in this paper are the medical model of disability and the social model of disability. The medical model of disability interprets disability as an individual's medical problem. Disability is inherently seen as abnormal – it is a defect, malformation, or failure of one's bodily system. In this model, physicians have the power to

medically diagnose one's condition as a disability acting as the gatekeeper to the individual with disabilities' access to resources (Retief and Letšosa 2018). On the other hand, the social model of disability emphasizes disability as a socially constructed phenomenon. It chooses to focus on how one's physical or social environment may impose a limitation on certain groups of people. It establishes that disability constitutes social oppression. In this model, it is societal change instead of individual adjustments, that is the solution to addressing disabilities (Retief and Letšosa 2018; Shakespeare 2006).

I then discussed the value and structures of Asian American families. Some Asian American communities may adhere to family structures and values that differ from that of mainstream Americans. These differences may be due to the influence of Buddhism, Confucianism, Taoism ideologies, and philosophies. These philosophies and ideologies instill obligations towards families and parents to maintain their family reputations (Ghosh and Magana 2009; Bui and Turnbull 2003; Wang and Casillas 2013). IDD is highly stigmatized and may bring shame to the family in some Asian cultures (Ghosh and Magana 2009). Thus, having a child with IDD in an Asian American family may be challenging because some caregivers may choose to isolate themselves and not seek out help to preserve their family's face. Furthermore, cultural, geographical, educational, and socioeconomic factors may contribute to a family's understanding of the causation of IDD. Some placed a greater emphasis on medical causes whereas others highlighted superstition or spirit as its main cause. AAPI immigrant values, perceptions, and knowledge about disability are influenced by their level of acculturation to mainstream American culture.

Even with some level of acculturation, Asian American families nevertheless face a multitude of barriers when seeking out resources for their children with IDD that White, middle-

class, and/or English proficient caregiver do not face (Cooc and Yang 2017). These may be due to linguistic barriers including, but not limited to, the lack of qualified translators and easy to read translated information and pamphlets. Additionally, the cultural differences between healthcare and social service professionals and caregivers may exacerbate this lack of mutual understanding (Thurgood and LaPolla 2003; Jegatheesan 2009; Hampton 2000). These scenarios stress the importance of culturally competent professionals and materials to accommodate families with different needs. Furthermore, there are other barriers such as socioeconomic barriers like medical expenses and geographical barriers like school districts that further hinder AAPI families from being able to receive the same access or quality of care that English-speaking, middle-class Americans do (Magaña, Parish, and son 2015; Jegatheesan 2009; Bui and Turnbull 2003).

This study focuses on three Chinese American immigrant family dynamics, their perceptions and understanding of their child's diagnosis of an Intellectual and Developmental Disability (IDD), and how their identities impact their experiences navigating the American educational, medical and social service system when obtaining the necessary care for their children. To understand their experiences, I conducted semi-structured interviews with three Chinese American caregivers. All three caregivers live within the greater Philadelphia region. They are immigrants themselves or they come from an immigrant family. The interviews with these three caregivers gave me insight into the challenges and considerations that these caregivers (whether they are siblings, parents, or other individuals who provide for the individual with a disability) must undergo to receive the services that they are entitled to. The interviews also highlighted the disparities and inequality in the quality and quantity of care that these families received. As Chinese American immigrant caregivers caring for a child with IDD, they

and their child/ren embody multiple marginalized identities. The intersectionality of their marginalized social identities exacerbates the impact of power and oppression in American society. Their experiences navigating the health, social and education institutions will differ from that of non-immigrant, English-proficient, upper-middle-class, White caregivers. As Chinese American caregivers, they experience systemic, political, racial, and cultural barriers that collectively contributed to the lack of support and frustration these caregivers faced.

Literature Review

Disability Statistics

While there are approximately 42 million disabled individuals and 4 million people diagnosed with developmental disabilities within the United States in 2017, Asian Americans reportedly have the lowest prevalence among all of the racial groups. Center for Disease Control reported that 1 in 10 Asian Americans has a disability whereas White, Black, Hispanic, and Native Americans range from 1 in 3 to 1 in 6. Pew Research Center reported 6.3% of older Asian Americans to have a disability, and within the working-age group (21-64), Employment and Disability Institute at Cornell University ILR School reported that 4.3% Asian Americans are disabled in comparison to their White counterparts whose prevalence is 13.9% and 10.2% respectively (CDC 2018; Bialik 2017; Erickson, W., Lee, C., & von Schrader, S. 2012). Furthermore, these statistics mask the disparities in health and access to resources among the diverse Asian American subgroups due to language, cultural, and political barriers. Limited language literacy, cultural hesitance to report disabilities, and omission of data due to AAPI's relatively small population (Holland and Palaniappan 2012).

History of Disability Rights Movement

The United States has a history of excluding individuals with disabilities and minorities from their civil rights. In the 1800s, laws and economic conditions prohibited Black, poor whites, and Native Americans from education and participating in society (Connor and Ferri 2013). The concept of disability also engendered a negative image of immigrants to the United States. The 1882 Undesirables Act gave immigration authorities the ability to screen immigrants and reject those who they perceive as “lunatics, idiots or unable to take care of themselves” (Connor and Ferri 2013; Baynton 2005). By 1907, Commissioner General of Immigration added “imbecile”

and “feeble-minded persons” to the exclusionary categories for immigration in addition to people with epilepsy (Connor and Ferri 2013; Baynton 2005).

Francis Galton coined the term “eugenics” in 1884 as a theory and practice that aimed to improve the genetic quality of humans by using science as a political tool to justify legislation and social perceptions that favored Nordic/Aryan traits, abled-bodied individuals from high social classes (Galton 1904; Osborn 1937; Hansen and King 2001). During the 1910s, the idea of eugenics popularized through society’s fear of racial pollution, disability, and poverty. By the 1920s, Harry Laughlin, a eugenicist at the Pioneer Fund in Cold Spring Harbor, NY influenced eugenics sterilization and immigration laws in both Europe, especially Nazi Germany, and the United States (Radford 1991; Connor and Ferri 2013). During the 1940s, Nazi Germany utilized Laughlin’s work to justify the sanction of Action T4, a policy to systematically euthanize over 200,000 people with physical and mental disabilities (Connor and Ferri 2013). On the other side of the ocean, between 1907 and 1944, the “official” sterilization count in America was about 42,000 people – 65,000 throughout 33 states, half of whom are from California (Radford 1991; Connor and Ferri 2013). Many of those sterilized in America were coerced, sterilized without their consent by the State, and at times, even without their knowledge. Native Americans, poor folks, disabled folks and African American women account for the highest percentage of sterilization (Connor and Ferri 2013).

In 1927, Virginia State Colony for Epileptics and Feeble-minded won the petition to sterilize Carrie Buck, a 17-year old “feeble-minded” girl whose mother and grandmother were suspected to also have “mental retardation” (Grenon and Merrick 2014). She had given birth to an illegitimate child who was suspected to also be intellectually disabled (ID). Justice Oliver Wendell Holmes, who presided over the case and an avid supporter of eugenics said:

“It is better for all the world if instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes... Three generations of imbeciles are enough” (Buck v. Bell, 274 U.S. 200 1927).

For the “feeble-minded individuals who were institutionalized”, sterilization became a precondition for their release. Sterilization is also needed in some states for individuals with ID for them to be able to marry. The case *Bucks v Bell* is infamous for its assumptions that mental disabilities are genetically transmitted (Connor and Ferri 2013; Ellis 2013). Moreover, it signified the abuse that individuals with intellectual disabilities had to endure throughout American history.

After World War II, the American Association on Mental Deficiency (now known as the American Association for Intellectual and Developmental Disabilities, AAIDD) was formed based on advocacy from parents with children with disabilities. And in the 1950s, advocacy for children with disabilities established organizations for specific disabilities such as the Muscular Dystrophy Association. These advocacy groups gained influence. They pressured the government, state legislature for accommodations, emphasized the need for special education alongside creating and developing grants and journals for disability research (Connor and Ferri 2013). By the 60s, President John F. Kennedy recognized “mental retardation”, a condition that affects the children of the country, as a social and economic concern that must be addressed by the country. His actions drew interests among professionals including researchers, educators, and doctors. He called on the national Mental Retardation panel which drew to light the violence and

abuse inflicted on individuals with intellectual differences including forced institutionalization, lobotomy, and infecting patients with the hepatitis virus for experimental purposes (Connor and Ferri 2013).

In the 1960s, the concept of Learning Disability (LD) was coined by Samuel Kirk. It illustrated the political nature of disabilities – almost exclusively only diagnosing white male children with LD. There was no biological or medical basis for this new categorization. The main goal of the categorization was to separate the white male children who are just “socially maladjusted” from children with other disabilities. Disability diagnoses are closely associated with individuals from “inferior” race, ethnicity, and social classes (Connor and Ferri 2013).

The Civil Rights Movement for African Americans and Women’s Rights movement became the foundation for equal rights activism of other minorities in society i.e. LGBTQIA+ and individuals with disabilities. The Disability Rights movement began in the 1960s, drawing awareness towards disability-based discrimination and the need to reform public spaces, resources, programs, and employment to make it accessible for individuals with a disability to participate in society. The Rehabilitation Act of 1973 outlawed discrimination of people with disabilities in federally funded agencies, programs, and institutions (Connor and Ferri 2013). This Act also ensured an anti-discrimination civil rights statute to provide reasonable accommodations to meet the needs of students with disabilities and gives people with disabilities the right to sue. The Federal Education of All Handicapped Children Act of 1975 furthered this by requiring all publicly funded schools to provide equal access to children with disabilities. To accommodate these children, their education programs must be individualized to fit their needs, their schools must provide procedural due process in the least restrictive environment, and allow parental participation (Connor and Ferri 2013; Grossberg 2011). These legislations induced and

popularized special education professionalization including school psychologists, therapists, counselors, and more.

1990 was an important year for Disability Rights Movement – The passing of the American with Disabilities Act (ADA) and reauthorization of The Individuals with Disabilities Education Act (IDEA) of 1990 from its predecessor of 1975. The ADA of 1990 outlawed barriers, both attitudinal and environmental barriers from employers, merchants, and government, and required them to accommodate people with disabilities with “reasonable accommodations” (Weber 2010; Connor and Ferri 2013). Within these contexts, interventions and rehabilitation services work to aid individuals to partake in community activities at a functioning level regardless of their disabilities (Chiang and Hadadian 2007). IDEA updated the discourse of the legislation to reflect an “individual first” approach. It also expanded disability categories and services to include developmental disabilities like autism and traumatic brain injury as well as rehabilitation counseling and social work services (Connor and Ferri 2013). Additionally, the law required schools to address the needs of culturally and linguistically diverse children and their families through the use of translation services, development of an array of assessments, and more. IDEA was amended again in 1997 further expanding the definition of disability. As a result, it raised concerns in the special education system like who should be labeled as disabled and what resources would they be provided (Connor and Ferri 2013). Another amendment of IDEA was made to establish the Individuals with Disabilities Educations Improvement Act (IDEIA) in 2004 as a result of the No Child Left Behind (NCBL) Act of 2001. IDEIA was created to be more synchronous with NCBL and ensured that students with disabilities in charter schools are entitled to receive special education services. In 2007, several other amendments were made to the same Act to ensure students with severe and

multiple disabilities can receive alternative assessment based on their modified academic achievement standards (US Department of Education 2007).

These civil rights laws have assisted in shifting the perception of individuals with disabilities in the United States over the last century. Some more recent changes to legislation that impact people with disabilities are the ADA amendments Act (ADAAA) in 2008 and the Affordable Care Act (2010) (US Department of Justice 2008; Reichel 2019). The amendment redefined “disability” to broaden the definition of disability to encompass more categories of people that would be protected by ADA and related non-discrimination laws (US Department of Justice 2008; Casey 2020). The Affordable Care Act of 2010 improved overall access to care for people with disabilities through expanded eligibility for Medicaid and Medicare. The insurance coverage rates for individuals with disabilities after ACA implementation increased. People with disabilities experienced a reduction of delayed or foregone care and now have a regular provider. The Act prohibited insurance companies from denying or restricting insurance coverage based on preexisting conditions, a problem that served as a barrier to health care for many disabled folks pre-ACA (Reichel 2019).

The history of the Disability Rights Movement illustrates the progress in American societal attitudes toward individuals with disabilities, specifically, individuals with intellectual and developmental disabilities. We saw the objectification and inhumane treatment of people with disabilities. However, we can also see how disability rights/civil rights advocacy influenced our society and changed societal perception and acceptance of disabilities in the last century. Current American legislations have been reformed on multiple occasions over the last 50 years to protect individuals with disabilities and to ensure equal protection and opportunities for them as for the able-bodied individuals. The legislations also help establish the resources that are

available or need to be made available to achieve those goals. Nevertheless, the societal perceptions and acceptance of disabilities within the United States extend beyond the aforementioned influence of American legislation and advocacy groups. They are also impacted by a multitude of factors; culture, language, race, religion, socioeconomic status, and more.

Construction of Disability

Our perception and experiences of our health, illness, and disability are heavily influenced by our cultural worldviews (Zechella and Raval 2016; Mereish 2012). Culture influences one's common perception and understanding of health conditions and treatments (Kleinman 1989). Symptoms and conditions interpreted by one community may differ from another. The current understanding and definition of disability are constructed by discourses predominantly based on Western biomedical measures. These include diagnostic, technical, and bureaucratized standards that the conditions must fulfill for them to be considered a disability. Biomedicine has become the commonly accepted medical system and therapeutic practice based upon Western theories of disease etiology. It is insistent on materialism as grounds of knowledge and heavily influences current discourse around illness, diseases, and disability. (Kleinman 1995). Biomedicine focuses on the biopathology as well as its mechanisms and courses to legitimize symptoms and conditions (Rosenberg 2002). The definition of "natural" in biomedical standards must be tangible. Interpretation of symptoms and "natural" developmental milestones differ based on the local cultural systems. What is considered natural is dependent on culturally shared understandings which differ amongst communities. Each social group has shared discourses like idioms and other terminologies to describe bodily conditions. Western societies perceive the objective body to be separate from emotions and thoughts. On the other hand, non-

western societies often regard the body, cognition, and emotions to be interlinked. (Kleinman 1989).

Clinical diagnosis of a disability is thus informed based on western ideals and norms. Through lab tests, pathology and biology-based thresholds, evidence-based risk factors, and more, biomedicine and bureaucracies, e.g. healthcare system, government or other institutions establish disability as socially legitimate diseases (Rosenberg 2002). Disease entities, under bureaucratic influences, acquire social elements and characteristics, shape practice patterns and institutional decisions, and can decide on appropriate treatment measures. Diseases also influence protocols, imaging, guidelines, diagnostic tools, and procedures that legitimize patients and their caregivers' reported signs and symptoms through diagnoses. Medicalization of conditions and symptoms through diagnoses is critical to defining and managing socially accepted notion of disease. Diagnosis of a disability is a cognitively essential ritual for the individuals diagnosed with disabilities as well as their families and caregivers. It is also bureaucratically essential for opening public, governmental, and private institutional resources, records, and complex interprofessional institutions (Rosenberg 2002). Additionally, it legitimizes the concerns and experiences that the individual and their family faced as the diagnosis becomes a reality in the family's life.

The diagnosis of mental conditions and illnesses has both the power to objectify and the power to benefit the individual affected (Ryang 2017). These conditions include atypical behaviors, delayed cognitive or mental developments, and limitations in their adaptive functioning based on societal demands like eating, socializing, and eye contact. Developmental disability diagnosis that is built upon the public and expert knowledge of mental illnesses and conditions induces the perpetuation of the illness without a debate about its legitimacy. During

the diagnosis, the individual is objectified into a medium that linked pathological concepts and institutionalized social power (Rosenberg 2002). The individuals are subjects of diagnostic practices that objectified them to sets of data, lab reports, and the symptoms they exhibit. The diagnosis of their condition establishes treatments and therapies for individuals with a specific illness or disease. On the other hand, the benefits of being diagnosed include access to medications, credible medical establishments, governmental assistance, educational, social, professional, and community supports. Diagnoses may also influence a shift in parental perceptions of the etiology of their child's condition (Rosenberg 2002; Ryang 2017). A medical diagnosis of a child's condition allows parents who blamed themselves for their child's condition to accept a medical, biological explanation for their child's condition. This may remove the stigma around their perception of their child's condition, so parents feel more comfortable seeking out care.

Additionally, individuals diagnosed with an intellectual and developmental disability often live with their family members or caregivers— AAPI families are no different. Families are a crucial component to the wellbeing of individuals diagnosed with IDD, especially children. Parents and caregivers understand the needs of their children the best and can advocate on their behalf. However Asian American caregivers of children clinically diagnosed with IDD experience unique challenges when obtaining quality care and resource due to cultural, linguistic, socioeconomic, health literacy barriers (Magaña, Parish, and son 2015).

Models of Disability

Ab/normality

The concept of normality, often taken for granted by able-bodied people, is imposed to the same societal standard on differently abled individuals. Michel Foucault's work emphasized the standardization of everyday life through concepts of law, states, professional associations, and cultural influences (Lock 2004). The concept of what is a "normal" and "acceptable body" including normalized behaviors, intelligence, and beauty, has been historically impacted by medicalizing and legalizing the body of a "normal" human. By questioning "Is the child normal?", highlights what traits are considered to be ideal, and excludes the traits that are "below" average, signifying abnormality (Baynton 2005). Norms thus follow the trends of a bell curve, emphasizing the common/normal variation of a condition and implying that the majority of the population should be a part of the norm (Baynton 2005). In our ableist society, individuals with disabilities or impairments, both physical and cognitive, are considered deviants. Thus, society will attempt to normalize the bodies of those who are "ab/normal" and "otherize" them until so (Baynton 2005).

By the 1800s, health and one's body is regarded to an extent, like a commodity under capitalism to which those with money, have the power to influence medicine and legislation on what constitutes as "normal".(Lock 2004). One's physical body can be improved upon and are expected to contribute to society. With the popularization of western medicine and medical interventions, the power of knowledge, and the power that western medicine has, heavily impact the consumer/capitalist market culture (Hancock 2018). Engines of the capitalist markets including pharmaceutical companies, biotech companies, and hospital systems are also engines of medicalization; they have the power to impact medical discourses surrounding health and

illnesses. Innovations in medical practice, knowledge, and technology consolidated the concepts of “anatomical pathological sciences” (Lock 2004) to construct a universally accepted representation of “healthy” and “normal” bodies. This ideology then influences the systemization and routinization of medical diagnosis and what constitutes as deviating from the “norm”. Those who deviate from that norm are alienated or excluded in our society (Lock 2004). These dualisms, health, and illness, ab/normal, establish the idea that able-bodied individuals are somehow “superior” and “better” to those who are differently abled and do not conform to the norm (Retief and Letšosa 2018). Development of treatments to “normalize” one’s body now require purchases of medication, medical technology, or potentially other products. As a result, the healthcare, medical and pharmaceutical industries have power in instituting resources and policies that impact those whose bodies or health deviated from the norm.

The Medical Model of Disability:

The medical model of disability emphasizes that the disability is a result of a physiological or biological impairment in body functions or structures, a deficiency or abnormality of the body are due to damages or diseases (Haegele and Hodge 2016; Llewellyn and Hogan 2000). In this model, disability is almost synonymous to having ill health or being sick. It is seen as a phenomenon that must be medically treated and “fixed” for the individual to partake in society. This focus on disability reinforces ableism in society (Haegele and Hodge 2016). Ableism is the social process of discrimination and biases against disabled people (Friedman and Owen 2017). It emphasized that the disability is on the individual, and not a consequence of their greater socio-economic, physical, cultural, and/or political environments (Haegele and Hodge 2016). This model extends the dichotomy of “normality” and

“abnormality”. Normality in the context of disability includes being able-minded and able-bodied. Any difference from these standards is considered abnormal functioning.

The model accentuates the importance of physicians as healers who provide care and individuals with a disability as patients who need and receive care in the process of being medically treated for their disability to achieve self-independence. These treatments justify the institutionalization and segregation of education systems that have been present throughout history to today, especially in neurodiverse populations and those with cognitive and developmental disabilities (Haegele and Hodge 2016; Shyman 2016). As a result, it cultivates the hierarchal, inequitable dynamic of power between physicians and patients. Medical professionals have the authority to legitimize one’s condition as a disability for the individual to gain access to resources and services including special education with individualized plans and accommodations that would otherwise be inaccessible for them (Shyman 2016).

However, the medical model is also referred to as the “personal tragedy model”. This model negatively defines disability. It is seen as ‘a personal tragedy’, an objectively bad and pitiable condition for both the individual and their family. The individual and their family may regard disability as something they could have prevented and hopefully can be ‘cured’ (Retief and Letšosa 2018). Disability was negatively politicized on the bodies of people with disabilities to reinforce the notion that people with disabilities are non-comparable to their able-bodied counterparts. Such an approach has led to a number of controversial “treatments” for their conditions. These include involuntary sterilization, euthanasia, confinement to institutions, and more (Retief and Letšosa 2018). The medical model also creates the duality between able-bodied individuals and those who are not, reinforcing derogatory discourse on “disabled” bodies with terms like ‘invalid’, ‘cripple’, and spastic (Retief and Letšosa 2018). It treats each individual’s

medical condition as problems that must be solved. This neglects the multitude of other aspects of the individual's life that may play into their health condition since it exclusively focuses on the limitations that are associated with the disability. This model also fails to take into account those who are medically considered disabled or chronically ill but do not perceive themselves as feeling sick, but instead have some impairments that "do not present as daily health concerns" (Retief and Letšosa 2018).

The medical model has also been criticized for assigning so much power over to the medical professionals. They can influence what conditions society consider as normal and low risk, and what is considered deviants from the norm, like the Body Mass Index (BMI). They have the power to medically diagnose an individual with a condition that is legally regarded to as a disability. This also makes them "gatekeepers" to resources access for individuals with disabilities. Such resources include requests and accommodations for smaller/independent education settings, social security, social services like a one-on-one aide, and Medicare (Shyman 2016).

The Social Model of Disability

The medical model of disability focuses on the concept of normalization and reinforces the marginalization of folks who are categorized as disabled (Llewellyn and Hogan 2000). The social model of disability, on the other hand, has been popularized especially among disability advocates. This model focuses on the socially constructed idea of disability which emerged from the preoccupation with the concept of normality, and the oppressive effects it posed on individuals with impairments. This model diverts the attention of the individual and their body to the "collective responsibility of society as a whole" (Llewellyn and Hogan 2000). It puts the pressure on society to modify the current rhetoric, perception and understanding of disability to

highlight how social, economic, environmental, and other factors influence the physical and psychological well-being as well as the level of disability one experiences (Llewellyn and Hogan 2000). Unlike the medical model which ultimately reduces disabled people's complex issues to matters of intervention, cure, and rehabilitation, the social model highlights the social oppression to instigate change (Shakespeare 2006).

According to the Union of Physically Impaired Against Segregation (UPIAS), there is a distinct conceptual difference between "impairment" and "disability" (Retief and Letšosa 2018). They defined impairment as 'lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body'. Disability, on the other hand, is defined as:

'the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus exclude them from participation in the mainstream of social activities' (1976) (Shakespeare 2006; Retief and Letšosa 2018)

The definitions provided by UPIAS distinguish 'impairment' as an individual, physical, and personal matter whereas 'disability' emphasized the relationship between an individual's impairment and society (Shakespeare 2006). Although these definitions excluded intellectual, developmental, and sensory disabilities, the concept of the distinction between the two can still be applied. Nevertheless, an impairment, whether cognitive, physical, or sensory, is universally constant. Its impact on an individual differs across cultures due to social and political ideologies and beliefs (Retief and Letšosa 2018).

Although the social model of disability is deemed a more progressive approach than the medical model, it still has its shortcomings. It enshrines the need for legislative changes for antidiscrimination, removal of barriers, and advocates for independent living for disabled

individuals (Shakespeare 2006). The social model highlights that disabled individuals are oppressed by society. It also emphasizes that the social oppression and exclusion that disabled individuals face are not a result of their deficits but rather a systematic social issue that was imposed onto them. Civil rights for disabled individuals in this model highlight the importance of having organizations and services be supervised by disabled individuals as they can provide and offer the best insight to solutions (Shakespeare 2006). However, the social model is not all-encompassing. It focused on removing barriers for those who are predominantly physically disabled and can convey their needs (Shakespeare 2006). As a result, it failed to include those who are neurodiverse and those with other limitations who may not be able to advocate for themselves and their needs as a part of the disabled community. For example, individuals with Autism must learn to adapt to an environment and society that was not designed nor adapted for them. They must partake in both the social skills curriculum in addition to the standard curriculum in school. The social model shifts the focus from the individual's needs to society's need to adapt to people with Autism. But this shift of focus disregards aspects of their lives including their emotional and communication needs and the diverse ways their needs are expressed, especially for those have limited speech and cognitive skills (Woods 2017).

Medicalization

The concept of medicalization was studied beginning in the 1960s by sociologists and popularized within academia throughout the 1970s (Retief and Letšosa 2018). Ivan Illich, a medical sociologist, discussed "iatrogenic harm" through the process of medicalization in his book *Limits to Medicine: Medical Nemeses* (1975). He critiqued that the aspects of daily life have been overinfluenced by biomedicine to a point of iatrogenesis. He categorized iatrogenesis into three levels; clinical, social, and cultural. Ultimately, his argument highlights how the

detrimental consequence of modern medicine, specifically medical interventions may worsen a patient's social or biological condition rather than benefiting them (Wright 2003). Illich and other early sociologists, including Michel Foucault and Irving Kenneth Zola conceptualized medicine as an agent of social control (Conrad, Schneider, and Gusfield 1992; Zola 1976; Conrad 1992a). Zola emphasized on the increasing medicalization of daily living conditions through the use of medicine to establish norms and labels of what is deemed to be "healthy" and "ill" (Zola 1976). Thus, medicine and health professionals and institutions influence our perceptions of health, what we constitute as medical conditions, and who is appropriate to consult when experiencing a perceived medical condition (Zola 1976; van Dijk et al. 2016).

Michel Foucault's work emphasized the idea of institutional surveillance on individual bodies and activities. He coined the terms biopower and the notion of panopticon to describe how government and other institutions like medicine effectively execute modern surveillance through functions like health assessments, diagnosis, and categorization of health conditions (Couch et al. 2015). Biopower describes the notion of how disciplinary institutions including prisons, hospitals, and states target individual bodies that deviate from the norm while simultaneously regulating the norms of the population through their knowledge and administrations (Taylor 2014). In conjunction with the concept of biopower, Foucault also theorized panopticon as the normalization of surveillance by social institutions i.e. hospitals and department of public health, in utilizing intricate examination functions like assessments, classifications, and diagnosis to objectify human behaviors and habits (Couch et al. 2015). Consequently, constant control over one's health resulted in self-discipline and self-surveillance. Thus, the ultimate medical social control is through the potential punishment of self-discipline (Couch et al. 2015).

Peter Conrad (2005), defined medicalization as “a problem defined in medical terms, described using medical language, understood through the adoption of a medical framework, or “treated” with medical intervention (Conrad 2007). He emphasized that medicalization can exist on the conceptual, institutional, and interactive levels (Conrad 1992). Conrad identified four main factors that influence medicalization: the authority and power that the medical profession possesses, directed professional and organizational activities and social movements and grassroots advocacy, pharmaceutical and insurance industries (Conrad 2005). Physicians have the power and capacity to directly participate in the process of defining the patient’s condition as medical or address their social situations with a medical intervention i.e. prescribing Ritalin for an individual who is on the brink of losing their job due to their hyperactivity and inability to focus on work. Likewise, medical institutions have the power and authority to adapt medical approaches that would best address specific medical conditions. (Conrad 1992). For example, medical institutions normalized the treatment of hyperactivity with prescriptions of Ritalin. These institutions participated in the process of medicalizing hyperactivity as Attention deficit hyperactivity disorder (ADHD) (Conrad 2005). Medicalizing the disorder legitimized and contributed to the spread of awareness and knowledge of the condition and treatment methods. On the broadest conceptual framework, the medicalization of a condition occurs by defining the condition as a problem through the use of medical discourse including medical terminologies (Conrad 1992). In the context of hyperactivity, the first addition of ADHD to DSM-III legitimized the problem as truly medical, with medical treatment and was categorized as a developmental disability (Holland and Higuera).

Social movements and grassroots advocacy were also prevalent in adult ADHD. ADHD was first incorporated into DSM-II as Hyperkinetic Reaction of Childhood in 1968. In DSM-III

which was released in 1980. The condition was reconceptualized to incorporate issues with attention, hyperactivity, and impulsivity. The term to describe the condition changed to Attention deficit disorder and ADHD in the revised version of DSM-III in 1987. In the 1980s, the DSM described ADHD as exclusively a childhood condition. However, books, articles, and websites published in the late 80s and early 90s publicized potential adult ADHD and its treatments (Epstein and Loren 2014). Furthermore, advocacy groups such as children and Adults with Attention Deficit and Hyperactivity Disorder (CHAAD) became leading advocates raising awareness, identifying, and treating adults with ADHD (Conrad 2005). CHAAD is a nonprofit consumer group made up of parents, patients, and other stakeholders who have ties to the disorder. CHAAD and their efforts are funded by the manufacturer of Ritalin, Novartis. This calls into question the boundaries between advocacy and corporate advertisement. The financial support and influence of Novartis may have incentivized CHAAD to emphasize the diagnosis and medical treatments of adults with ADHD. The medicalization of ADHD, a learning disability, was heavily influenced by biomedical, social, and financial stakeholders in the United States. It brings one to question how such a condition is perceived, diagnosed, and treated in other countries.

Health professionals not only have the power to prescribe medication and normalize conditions, but they also have an increasing influence on the medical interventions and prevention methods available for a condition. They have the authority to convince their patients, and potentially society, that they should practice specific habits on the premise of medicine and health. Health professionals establish social intervention controls in traditional diseases as well as the more “social ones” (Zola 1976). For example, in the cases of preventing cardiovascular or liver diseases, physicians will utilize medical discourses to recommend individuals to change

their diets, exercise habits, and/or alcohol consumption. There is increasing pressure from physicians, advocates, and individuals affected by the condition towards at-risk individuals, society, and industries to act on and abide by suggested intervention methods. These include an increase of heart-related dietary supplements, limiting tobacco sales by imposing the tobacco sales tax for heart and lungs as well as recommending moderate alcohol consumption for liver health (Zola 1976).

Social constructionism framework reevaluates what society defined as an exclusively natural phenomenon by emphasizing its cultural, social, and historical aspects. It explores the ways perceived realities and knowledge are produced through the influences of individuals and groups. In this framework, it embraces the social construction and dimensions of illness (Conrad and Barker 2010). Through this model, medical professionals can influence the societal acceptance of specific behaviors and habits as an illness, which then becomes a problem that must be addressed or solved by society (Zola 1976; Conrad, Schneider, and Gusfield 1992). In the context of disability, health professionals serve as the gatekeeper to medical diagnoses, treatments and access to disability benefits (Conrad 1992). Medical discourses construct our knowledge of the body and thus can affect the legitimacy of one's condition. A medical diagnosis of conditions like autism, cerebral palsy, intellectual disability (ID), and down syndrome formally establishes the right for the individual of the condition to receive specific benefits and accommodations they are entitled to in accordance with the institutions and the American with Disabilities Act (ADA). These accommodations include access to individualized education programs in special education, recorded books, vocational therapy, one-on-one aide, and assistive technologies (Center for Parent Information and Resources 2017).

(Biomedical) Diagnosis, Treatments, and Resources for individuals with IDD

Furthermore, intellectual and developmental disability is a generalized term that encompasses multiple conditions, and thus, diagnostic measures, treatments, and resources available for individuals also vary (Moeschler, Shevell, and Genetics 2014). AAIDD defines intellectual disability through measuring one's intelligence (IQ), adaptive behavior, and the systems of support afforded the individual. ID originates before the age of 18. Developmental disabilities/delays must include a delay or nondevelopment in two or more of the following domains: fine or gross motor, speech/language, cognitive, social/personal, and daily activities for a living (Moeschler, Shevell, and Genetics 2014). These include chromosome microarray; child's medical and family history; physical and neurologic examinations for neurologic or behavioral signs; and other consultation methods to establish a diagnosis and further care (Moeschler, Shevell, and Genetics 2014). Collectively, these diagnostic examinations, considerations of environmental factors, and blood test results help healthcare professionals understand the complexity of the individual's condition (Cobb, Hinks, and Thomson 2014). The cause of these conditions may be solely due to genetic or chromosomal mutations, like down syndrome or fragile-X syndrome, or it may be a complex combination of genetic and environmental risks like Tourette syndrome, autism spectrum disorder (ASD), and juvenile idiopathic arthritis (JIA) (Cobb, Hinks, and Thomson 2014; Sun et al. 2015). In the absence of genetic or biochemical markers, assessments should also be based on detailed developmental history in accordance with Diagnostic and Statistical Manual of Mental Disorders (DSM V) and/or (International Statistical Classification of Diseases and Related Health Problems (ICD 10) (Keenan et al. 2010)

Planning and monitoring one's IDD extends beyond just the biomedical aspects like taking medication or surgery, to include community and educational services. Some examples of

these services include; providers referring parents to Special Education Needs Statements (SENS); Individual Education Plan (IEP); Early Childhood Intervention; and Person-centered planning (PCP) (Keenan et al. 2010). Parenting intervention programs like Incredible Years and Parent Plus programs implement cognitive-behavioral approaches in teaching parenting skills, focusing on cognitive-behavioral strategies (Petrenko 2013). The National Institute of Mental health suggests different treatment methods that vary from behavioral, speech to occupational-related therapy such as cognitive behavioral therapy, occupational therapy, speech-language therapy, physical therapy and social skills training just to name a few (Office of Communications NIH 2017). Likewise, similar treatments, in addition to assistive devices and other drugs and supplements are suggested for Down Syndrome (NIH 2017)

Values and structure in Western and Asian Families

By understanding Asian families in their unique environmental, cultural, and religious contexts provide us with a clearer picture of families of children with IDD. Asian American communities have some family structures and values that differ from mainstream Americans. Although there is much diversity within subgroups of Asian Americans, they do share some common familial values (Ghosh and Magana 2009). These traditional familial values originated from and are highly influenced by Buddhist, Confucian, and Taoist ideologies and philosophies. Large Asian American populations groups, including Cambodians, Chinese, Japanese, Laotian, Thai, and Vietnamese Americans practice Buddhism (Hampton 2000). Buddhist values emphasize self-negation, self-sacrifice, modesty, compassion, and humility (Ghosh and Magana 2009). Confucian philosophy, which is most prominent in East Asian culture like Korea, China, and Japan, stresses filial piety towards authority and the elderly; interdependence on, obligation, and loyalty to their family; and high regard for education. Taoist ideologies are the most

influential on Chinese Americans, the largest ethnic group in Asian American communities. Taoism encourages the maintenance of harmony in relationships, simplicity, avoidance of confrontations, and charity (Bui and Turnbull 2003; Wang and Casillas 2013; Hampton 2000). Taoism emphasizes the balance of the Yin and the Yang – neither of the entities exist in absolute states. Unlike biomedicine which separates the mind and the body as separate entities, Traditional Chinese Medicine regards the mind and the body as a whole. The imbalance of the Yin and the Yang in an individual's body creates a disharmony that results in illness. Disability in this context is the result of such pattern and disharmony. One must restore the balance of the Yin and Yang to heal the diseases and disabilities they embody. These ideals may contribute to Asian families' reluctance in accepting their child's clinical diagnoses and the belief that their child's condition is only temporary (Hampton 2000).

Asian American families, especially immigrants from collectivist nations, primarily retain collectivist values because their life satisfaction is influenced by social and cultural norms like Confucian ideologies and morals (Ghosh and Magana 2009; Suh et al. 1998). Although mainstream Americans in the individualist nation of the United States, emphasizes personal emotions when rating life satisfaction, Asian Americans are more likely to downplay the importance of their emotions by emphasizing social appraisals and abidance with social norms (Suh et al. 1998; Okazaki and Kallivayalil 2002). Confucian ideology about filial piety stresses individual responsibilities to their families and the community. Individual's capabilities are evaluated through their contributions to their community. Thus, decisions are often made based on what is most beneficial to the community and not to the individual (Hampton 2000). Under Confucian philosophy, parents assume their parental duty of teaching and training their children the principles of filial piety and social courtesies (Wang and Casillas 2013). Confucian morals

also emphasize collaboration and cooperation in extended families. Asian Americans who live by Confucian philosophies depend on their family members for support and resources. They heavily value interdependency in their relationships to strive towards common goals that would benefit the family as a whole.

In contrast to the individualistic culture that Americans embody, many Asian cultures regard individual successes as the product of the efforts of nature and the people around them (Bui and Turnbull 2003; Ghosh and Magana 2009). Confucian ideals thus instill strong feelings of obligations towards their families and parents. Moreover, filial piety and many Asian cultures normalize gender roles. Mothers take on the primary role of the caregiver. Asian American mothers who value family over personal goals and success will see themselves as sacrificing for the benefit of the family, to enhance and maintain their familial reputations. Mothers may feel that it was their fault that their child has a disability and thus feel a sense of obligation towards their child (Wang and Casillas 2013; Bui and Turnbull 2003).

Giving birth to a child diagnosed with a disability can be challenging. Parents may undergo feelings of stress, anxiety, denial, fear, grief, and more (Lo 2010). These feelings are nonspecific to Asian American parents. Caregivers with children diagnosed with IDD often also experience feelings of disempowerment. Additionally, caring for the child may become the dominant family activity which may impact familial stress, relationships, and financial stability (He 2017). Parents fear stigmatization and isolation from society because of their child's condition. Many Asian communities expect families to take and fulfill the needs of family members with disabilities (Baker et al. 2010).

Culture not only contributes to the perceived causation of disabilities but also shapes one's attitudes towards individuals with disabilities (Ghosh and Magana 2009). Asian American

attitudes toward disabilities generally differ from the Western culture which idealizes independence, competitiveness, autonomy, and change. Asian American subgroups may also hold varying perspectives on intellectual and developmental disabilities due to different religious, cultural, or familial beliefs (Bui and Turnbull 2003; Lo 2010). Nevertheless, Asian cultures generally share beliefs, values, and attitudes collectively among the unit to which the individual diagnosed with a disability belongs. A child with a disability that does not manifest itself physically may often be perceived as being abled (Bui and Turnbull 2003; Ghosh and Magana 2009). Thus, many Asian families choose to keep their child's diagnosis private because intellectual and developmental disabilities are highly stigmatized as bringing shame to the child and the family, causing them to lose face and reputation within their community (Ghosh and Magana 2009).

Education is held to a high regard in many Asian American communities. However, it must be recognized that the value of education is not perceived to the same degree of importance across Asian American communities (Xie and Goyette 2003). In the AAPI communities that do hold education to high regard, parents believe that academic success is the child's obligation towards the family, so they expect exceptional grades from their children. These extremely high expectations for their children serve to advance family social status, honor, and welfare, especially in immigrant families. Children's success is the family's success. Education for them is an opportunity for social mobility (Xie and Goyette 2003; Ghosh and Magana 2009). These strict expectations are reflective of both the authoritarian and authoritative parenting styles Asian parents execute. Authoritarian parenting style encompasses child obedience and parental strictness whereas the authoritative parenting style focuses on parental acceptance and responsiveness. Consequently, the child's misbehaviors and inability to fulfill academic or

employment success cause shame and embarrassment to the family (Wang and Casillas 2013; Lo 2010). Children diagnosed with intellectual and developmental disabilities often have difficulty with and do not adhere to the traditional academic assessments and expectations. Therefore, these Asian American parents with a child diagnosed with IDD may have to relinquish their high educational aspirations for their child. These parents then may have to accept their child's condition and have fewer rigid expectations for their child, especially in terms of their productivity (Wang and Casillas 2013; Lo 2010)

Cultural, geographical, and socioeconomic factors may all contribute to individual understanding causation of the IDD. Some families believe that a child born with a disability is due to bad spirits, bad karma, negative behaviors, or mistakes made by the parents or ancestors. Others believe that their child's condition is God's will or a violation of the natural order of events (Holroyd 2003; Ghosh and Magana 2009). A few qualitative studies conducted on Chinese families with children with IDD showed that some mothers believe that their child's disability was caused by their culturally inappropriate diets, the ingestion of medication, violation of taboo such as extramarital affairs during pregnancy. As a result, these mothers often took on the blame for causing their child's disability (Lam and Mackenzie 2002; Holroyd 2003; Ghosh and Magana 2009; Wang and Casillas 2013). In another study of caregivers in Afghanistan, those who reside in urban areas placed greater emphasis on medical causes including poor prenatal care as the cause of IDD, whereas those who reside in rural areas highlighted superstitions, fate, or spirit as the causation. These varying understandings about the causation of disability are not generalizable for everyone. Other factors that may contribute to one's understanding of disability includes access to biomedical service, education level, socioeconomic status, and knowledge about disabilities (Ghosh and Magana 2009).

Asian parents may interpret having a child with developmental delays as their inability to guide and provide proper parenting rather than a disability. Children with mild conditions that delay normative developmental milestones, especially in schools are perceived as lazy, defiant, or unmotivated (Cooc and Yang 2017). Families are highly aware of their societal reputation, so they collaborate to uphold their status. In societies where giving birth to a child diagnosed with a disability may cause these families to lose face, families, especially mothers of children with IDD are socially discriminated against by people within their community and in broader society (Wang and Casillas 2013). In an attempt to uphold their honor, Asian American families may avoid seeking help and deny intervention services and support in an attempt to avoid shame and save face. However, this leaves these parents dependent on themselves and self-reliant strategies instead (Bui and Turnbull 2003; Ghosh and Magana 2009)(Bui and Turnbull 2003; Ghosh and Magana 2009).

On the other hand, Asian families can have a positive perception of their child's condition as a gift from God. Some Hmong and Filipino families may consider medical disabilities such as epilepsy, as signs of good luck. As a result, they are reluctant to change their child's situations and avoid or resent professionals who do not respect their views are resented and avoided (Jegatheesan 2009; Bui and Turnbull 2003). In response, Asian families are reluctant to receive care from their communities because they see it as inappropriate. Cultural norms influence parent's attention and interpretation of developmental milestones, which in Asian families, may differ from the Western norms (Zechella and Raval 2016). These perceptions and beliefs about causes may contribute to delayed clinical diagnosis of intellectual and developmental disabilities and parental choices on treatment type and professional resources they seek for their child's development (Bui and Turnbull 2003; Zechella and Raval 2016).

Studies have shown that Asian Americans underutilize available mental health services for a multitude of reasons which include language proficiency, stigmatization, beliefs, and attitudes towards mental health (He 2017; Jang et al. 2019). Kleinman explained that the Chinese use of the word “neurasthenia”, which means nerves or spirit is weak, to explain psychiatric problems as the term to provide a legitimate physical disease label for mental conditions that are culturally less accepted (Kleinman 1989). Thus, autism and other developmental disabilities are more well-known and accepted in Western society than in China and Chinese communities. Some Chinese parents seek treatments to cure their child’s developmental disability through different therapeutic mediums like acupuncture, or believe that their child’s condition can be cured (Wong et al. 2004). The linguistic and cultural differences between professionals and Asian American families with limited English proficiency pose a challenge in providing mental health care. They may feel more comfortable confiding in mental health professionals, or other spiritual leaders that speak their language (He 2017; Tuzon et al. 2017). However, there are limited professionals who speak multiple languages. Thus, parents who encountered dismissive providers, unqualified translators, impatience, and lack of sensitivity may understandably feel stressed and frustrated when reaching out to mental health professionals (Jegatheesan 2009).

The Effects of Acculturation

Acculturation level, also defined as the assimilation into mainstream (American) culture, is an important factor in influencing the attitudes and perceptions about disabilities cross-generationally (He 2017; Wang and Casillas 2013). First-generation immigrant parents may maintain their traditional values and gradually adapt to parts of the American way of life; whereas their children, second-generation individuals may quickly adapt to western thinking, customs, and social relationships through exposure to school and peers (He 2017; Fox, Thayer,

and Wadhwa 2017). Acculturation and education levels strongly affect AAPI's approach to disability. Wang and Casillas found that parents from Taiwan and Hong Kong, both with cultures that are more aligned with Western thinking, as well as highly educated parents do not view disability as a source of shame but attributed to environmental and genetic factors. They are optimistic about the educational resources and legal protections established for individuals with disabilities. (Wang and Casillas 2013; Cooc and Yang 2017). On the other hand, recent immigrants may be less familiar with the services and rights they are entitled to. As a result, they may have a more negative perception of disability being a fixed trait (Cooc and Yang 2017).

The segregated rate of assimilation for generational immigrants into the American mainstream and the effects on the second-generation immigrants are the premises of the segmented assimilation theory (Piedra and Engstrom 2009). Based on the segmented assimilation theory, immigrants, especially non-highly educated immigrants, settle in poorer inner-city neighborhoods, often close to or within co-ethnic communities. Geographic locations and the types of neighborhoods do affect one's process of acculturation and access to resources (Fox, Thayer, and Wadhwa 2017). Asian American immigrants that live within their ethnic communities, i.e. Chinatown or Koreatown, are more likely to preserve their heritage because they do not often interact thus rarely exposing the practices or values of the "American society"(Ghosh and Magana 2009). As a result, the limited English proficiency these folks have may affect one's health-related behaviors, caregiver's access to healthcare, and the quality of healthcare available for individuals with disabilities (Fox, Thayer, and Wadhwa 2017). The effects of language barriers will be discussed later in the literature review. These children often attend underfunded, highly segregated inner-city schools that do not provide the same resources for children, especially those with special needs, as they do for those living in wealthier

neighborhoods (Xie and Greenman 2011). On the other hand, living in a predominantly White, or Americanized neighborhood may speed up the process of acculturating, learning the language and learning about how different institutions and systems work. However, in this scenario, some studies suggest that it may also expose immigrants to various psychosocial stress including the stress to adapt to a new culture, and an increase in racial, and/or institutionalized discrimination by the majority community. (Fox, Thayer, and Wadhwa 2017; Clough, Lee, and Chae 2013).

The level of acculturation and education of the caregiver impact Asian immigrants' beliefs on causation and treatment of disabilities. College educated Korean American women held beliefs on causation that is consistent with the mainstream biomedical culture. They are able to identify and respect such cultural beliefs even if they do not endorse the beliefs themselves. Likely, one may simultaneously hold both Western and Eastern beliefs and visit both healers for treatments (Erickson, Devlieger, and Sung 1999). Likewise, Chinese American caregivers may also seek both mediums of treatment (Ryan and Smith 1989). These studies show that there are differences in beliefs about disabilities based on the level of acculturation among immigrant groups and families in their country of origin. They may retain some beliefs from their country of origin but also adapt to the mainstream American beliefs and attitudes.

Barriers to Care

Asian American families face a multitude of barriers when seeking out resources for their children diagnosed with intellectual and developmental disabilities. Language is a prevalent barrier for many Asian American parents with limited English proficiency when interacting with professionals. Locating the few bilingual translators available for Asian American populations may be difficult because of the diverse languages and dialects of the AAPI communities (Cooc and Yang 2017; He 2017). Asian American parents are also given the materials like pamphlets

about the diagnosis in English to bring home. Without translated materials, AAPI caregivers may have difficulty comprehending the information and medical terminologies on the pamphlet (Jegatheesan 2009). For Chinese American families and other minority families who speak specific dialects, it poses a substantial challenge to find support who speak the same dialect. Within China, there are eight prominent spoken dialect/language groups. They are mutually intelligible from one another which collectively includes hundreds of dialects. For those who only speak one dialect, communication with Chinese-speaking professionals may still pose a challenge. (Thurgood and LaPolla 2003). These language barriers limit parents from fully understanding their child's diagnosis which then impacts their ability to include and explain to their extended family members about the child's conditions too. Even when there is a translator, parents have reported that the translators are not qualified and lacked adequate background information and knowledge in both their native language and the English language to interpret the information shared by professionals efficiently, leaving out critical details (Jegatheesan 2009). This prohibits parents from asking professionals questions. Language barriers also prevent AAPI caregivers from being fully aware and comprehend disability-related laws and service systems in the United States such as the Individualized Education Program for their child (IEP) (Hampton 2000).

Moreover, cultural differences between healthcare professionals and parents may exacerbate their lack of mutual understanding. Different cultures have different discourses to describe symptoms and illnesses. For physicians and patients/patients' family to competently communicate their understanding of their child's condition, there must exist mutual interpretations and vocabularies (Kleinman 1989). However, with Asian American families, especially immigrant families, there may not exist terminologies to describe the diagnosis in the

caregivers' native language. Thus, caregivers are unfamiliar with their child's condition that is presented by their physician. In the Hmong language, there is no vocabulary for Down Syndrome and thus one must take the time to explain the condition for Hmong parents to understand (Baker et al. 2010a). The difference in the cultural understanding of the same condition may also lead to conflicts in patient-physician interactions. In biomedicine, epilepsy is considered a developmental disability. However, in Hmong culture, epilepsy is known to be *qaug dag peg*, translated to "The spirit catches you and you fall down", is considered to be a divine gift. Those with the condition are blessed to become a shaman. In the story of Lia Lee told by Anne Fadiman, the cultural clashes between biomedical and Hmong interpretations ultimately led to preventable irreversible health consequences for baby Lia (Fadiman 2012).

Evident in Lia's case, physicians in the American healthcare system are not all culturally competent. There is a shortage in physicians who can understand the cultural uniqueness of AAPI families, their beliefs and behaviors, and have the skills to work with them effectively to determine what is best for their patients (Hampton 2000). Furthermore, Physicians reported a lack of sufficient training throughout their education and exposure to individuals diagnosed with an intellectual and developmental disability. For Asian American families, that is doubly detrimental to their child's care (Magaña, Parish, and Son 2015). Parents have also reported physicians who apply stereotypical perceptions of Asian culture, values, and beliefs have intercepted their capacity to provide quality care. Asian families may rely on ethnomedicine as an essential treatment method for their child. However, some physicians are often quickly dismissive of any non-biomedical therapy methods. Parents have also reported experiences in which doctors were dismissive of their concerns because the parents were raising the child in

bilingual families with the explanation that children from multilingual families are more likely to be late talkers (Jegatheesan 2009).

AAPI families also struggle with other barriers that prevent them from accessing the care that they need. Minorities and immigrants are predominantly in a lower socioeconomic class than their white counterparts. As a result, these impact the resources and care that they have available to them (Baker et al. 2010b). These include the financial barrier to purchase insurance for themselves and/or for their families. For caregivers with children with disabilities, their children (under the age of 18) have the right to Medicare and potentially Medicaid (Jegatheesan 2009). However, family finances dictate their ability to also access resources like transportation to transport them and their child to appointments. Furthermore, if families cannot afford the medical expenses due to financial constraints, it also limits their ability to access care (Baker et al. 2010b). As a result, health disparities among racial minorities and white individuals are evident. Lower-income racial minorities receive less healthcare intervention and poorer quality of health services than their white counterparts (Bui and Turnbull 2003; Magaña, Parish, and son 2015).

Addressing Barriers

To address the health disparities experienced by individuals with disabilities from racial/ethnic minority groups, professionals must take into consideration the diverse values, practices, and sociocultural experiences when providing care (Dyches et al. 2004). To bridge this, professionals must restructure their care to approach their patients based on one's situation (He 2017). They must help their patients and the patient's caregivers, especially those with disabilities, adapt to the loss of potential dreams and hopes they had and establish a plan about how they can accept change in their lives and their children's lives. This may help reduce stress

and increase self-efficacy for patients and caregivers alike (He 2017; Clough, Lee, and Chae 2013)

It is also important to ensure that caregivers are connected with health professionals like racial minority doctors and nurses, who share similar vocabularies and understandings or who are culturally competent in providing care for minority folks with disabilities (Baker et al. 2010b). Magaña et.al. stated the need for professionals to be trained in patients with disabilities throughout their course of medical school. Currently, the compounding effects of limited providers trained in working with families and children with IDD and the cross-cultural differences contribute to the racial, health and healthcare disparities within such vulnerable populations (Magaña, Parish, and son 2015). Ultimately, training healthcare providers and even other professionals to be cultural brokers may help bridge the aforementioned disparities, as well as the gaps between providers and minority caregivers/families. These include becoming experts in the available health and community support services and how to access it alongside their professional care. Moreover, the professional communities that work with children with disabilities should expand the definition of healthcare providers to accept and include shamans, priests, herbalists, and other healers. Providers should also consult with community-based organizations on the best ways to support caregivers and their patients through adequate coordination (Baker et al. 2010b)

A possible approach to planning for a culturally diverse family with an individual with a disability is adapting to person-centered planning (PCP) (Bui and Turnbull 2003). It directs life changes for the individual with disability towards community and social inclusion through their friends, family, and community resources. This approach transforms traditional power relationships between caregivers and individuals with a disability. It gives the individual the

autonomy and focuses the plan based on their goals and preferences over the availability of resources (Bui and Turnbull 2003). Under the IDEA Act, the individual education plans (IEP) developed for students with special needs provides them with a meaningful level of planning for their future. Such an approach focuses on the plan on the individual's goals and preferences over the availability of resources. It transforms the traditional power relationships between caregivers and the individual with a disability (Bui and Turnbull 2003; Callicott 2003). It brings together people who are the most involved in the individual's life to establish open communication and a more cohesive home-school collaboration (Keyes and Owens-Johnson 2003). Person-centered planning respects the unique characteristics, qualities, talents of the individuals, and their family including race, culture, language to name a few. Ultimately, the goals of PCP IEP include independence, ability to express emotions in a socially appropriate way, money management, self-advocacy, and relationship for the focus individual. For a successful PCP IEP, professionals must ensure that the needs, concerns, and expectations of the individuals and their caregivers are prioritized (Keyes and Owens-Johnson 2003; Callicott 2003).

Asian American caregivers with children with disabilities benefit from additional emotional and psychological support from support groups to replace the loss of traditional support provided by extended family members as a result of geographic barriers and societal changes (Bui and Turnbull 2003; Zechella and Raval 2016). Public schools currently do not have the resources to provide training and support culturally diverse caregivers with children with disabilities (Lo 2010). Parent support groups provide caregivers with children with disabilities space, resources, and support that equips them to be advocates for their child. Moreover, it serves as a space where caregivers share skills and gain knowledge to cope with their children's needs and improve their attitudes and skills about parenting (Lo 2010). Moreover, Lo's research

provided evidence that for caregivers with limited English proficiency, their support group shared knowledge about additional resources for their children. Through participating, the immigrant parents developed a sense of trust and belonging, feeling less isolated because of their child's condition. Parents also feel more confident and empowered about their parenting skills and navigating their child/ren's special needs (Lo 2010).

Intersectionality of identities

Preliminary research presented that disability rates are drastically different between Asian Americans and other racial groups. Center for Disease Control (CDC) reported that 1 in 10 Asian Americans reported having a disability, whereas the statistics for disabilities for other racial groups are between 1 and 3 and 1 and 5 (CDC 2018). People living with disabilities face several oppressions including socioeconomic, education, and health disparities. Furthermore, there is a scarcity of research on racial and ethnic minorities with disabilities, especially those who are diagnosed with intellectual and developmental disabilities (Mereish 2012). The literature becomes even narrower with a focus on AAPI identities. The intersectionality of multiple marginalized social identities exacerbates the impacts of power and oppression on Asian Americans with disabilities, accelerating their disability trajectories (Mereish 2012). AAPI's with disabilities, like other racial and ethnic minorities, may routinely experience societal, institutional, and structural oppression and discrimination due to ableism and racism (Mereish 2012).

The experiences of AAPI with disabilities do not subject to the prototypes of either AAPI or disabled individuals' experiences. Rather, AAPIs with diagnosed disabilities experience intersectional invisibility, a term coined by Purdie-Vaughns and Eibach (Purdie-Vaughns and Eibach 2008). Intersectional invisibility is defined as "the general failure to fully recognize

people with intersecting identities as members of their constituent groups” (Purdie-Vaughns and Eibach 2008). Intersectional invisibility distorts “the intersectional persons’ characteristic to fit them into frameworks defined by prototypes of constituent identity groups” (Purdie-Vaughns and Eibach 2008). This framework highlights that individuals with multiple identities experience multiple forms of oppression due to androcentrism, ethnocentrism, and heterocentrism (Mereish 2012; Purdie-Vaughns and Eibach 2008). This leads to the marginalization of individuals like AAPIs with disabilities and their struggles to be underrepresented or recognized in society. They are commonly deprived of representative intersectional narratives in history, by alleged inclusive advocacy groups in politics, and are often mischaracterized and misunderstood in society (Purdie-Vaughns and Eibach 2008). These extensive oppressions result in legislative and societal neglect of those with intersectional identities.

AAPI with disabilities, especially those with invisible disabilities like intellectual and developmental disabilities, are even more marginalized than those who are physically disabled. The invisibility of mental disabilities or chronic pain in one’s body institute another marginalized and an often-overlooked group in society, resulting in a lack of resources, support, advocacy, and more. These barriers, structural, socioeconomic, systemic, political, cultural, and others, all contribute to AAPI experiences with, perception of, and resources sought for those with disabilities. AAPI parents and caregivers of a child diagnosed with an intellectual or developmental disability will be influenced by these factors when deciding their child’s care that may be different from non-immigrant American parents (Wang and Casillas 2013).

Methodology

Justification for the study:

This study focuses on the role of the medicalization of ab/normal mental conditions as intellectual and developmental disabilities and the impacts it has on Chinese American families and individuals who were diagnosed. Chinese American children who are diagnosed with an intellectual and developmental disability in the US are unique in their interactions with both their ethnic and American culture, their healing practices, and parenting styles. Traditionally, the most effective approach in understanding one's experience navigating a complex system is to interview the individual who is directly impacted by the system. However, the vulnerable status of children and disabled individuals identified by the department review committee (DRC) and the Institutional review board (IRB) restricted their participation. Moreover, the two identities, of being both a child and as an individual with an intellectual and developmental disability, the concerns about their agency, informed consent, and personal autonomy are contested. Children cannot fully provide consent without the approval of the parents. Even past those barriers, my training does not provide me with adequate skills to work with children with intellectual and developmental disabilities.

Healthcare providers were not the most appropriate participants for this study as well. There are inherent power dynamics between the interactions between healthcare personnel and the patient/patient's families. Healthcare providers, even those who work specifically with neurodiverse children are more often than not, trained by biomedical professionals. Thus, healthcare providers would be able to only provide limited and biased information on the experiences, resources, and perceptions that AAPIs have on IDD and both familial and individuals' living with the condition. I reached out to two physicians working at a well-

established institution in their Center for Neurodiversity and both confirmed that they do not often interact with AAPI families raising a child with IDD in their practice. Most of their experiences were working with predominantly English-speaking White families and rarely with Asian American families and cannot speak directly on the behalf of AAPI families.

Interviewing parents and/or caregivers of children with special intellectual needs would bypass both IRB and DRC regulations and obtain both familial, personal, and child/ren's narratives on their perceptions and interactions with the medicalization of their condition. It would provide us with insight into the different factors that were taken into consideration by parents and/or caregivers when opting for resources for their child. Parents and family members are the ones providing long-term care and have the biggest influence on their child's life. Not only are they responsible for the physical care of their child, but they also coordinate their child's various education, medical, and developmental interventions (Murphy et.al.). Besides, they are the ones who are most attentive to their child's everyday needs, behaviors, and growth. They are also legally the proxy for their child until the child is deemed competent to make informed decisions (through screenings and age) if they can. Caregivers interact with professionals and make decisions on behalf of their children. Consequently, the child's condition affects the caregiver on both a micro and macro level, emotionally and socially. By understanding caregiver's perceptions of the child's condition and their experiences with the healthcare system, it will become evident to us what motivates the caregivers to make the decisions of care for their child.

Positionality:

I recognize that my positionality as a Chinese American immigrant, young, able-bodied, and college-educated woman with plans to pursue Western medicine and healthcare, I will not

fully understand the experiences of these caregivers. As a Chinese American immigrant, I understand the complexity and often struggles with immigration and adapting to American society. This understanding may positively influence and help establish rapport with AAPI parents and caregivers. However, as a Chinese American immigrant with a college-degree education, I may be more assimilated to the American culture than the caregivers I interview, which would not only affect my interactions with the caregivers during the interviews but also possibly affect my ability to connect with them. I also am cognizant that as a woman who has not had a child, I will not understand the experiences, stress, or struggles they had undergone and will not assume that I do. As an able-bodied individual with no family members or close ones with a formally diagnosed intellectual and developmental disability, I lack any understanding of what it is like to have a family member who is diagnosed intellectual and developmental disability as well as what it is like to care for them. Furthermore, my plans to pursue a career in western medicine working in the American healthcare system influence my understanding of intellectual and developmental disability from a Western, biomedical approach. Although I am aware of and acknowledge how the Chinese community perceives and stigmatizes any “non-normal” mental health conditions and anyone with it, I cannot assume that I know how other Chinese communities perceive and approach such conditions.

Design

Each participant signed a document that has a general overview of the study to indicate informed consent. I have noted in the document, and before the beginning of the interview, repeated to the participant that they do not have to answer any questions that they do not feel comfortable answering. I then gave a verbal overview of the study and stated that there may be aspects of the interview where they may feel a bit uncomfortable so, they are free to stop the

interview at any point. Additionally, I tried to minimize my notetaking so that I am engaged in the conversation and that the conversation can flow as naturally as possible. The study's protocol was reviewed and approved by Swarthmore College Sociology and Anthropology departmental review board. All participants have provided their informed consent.

I conducted a semi-structured interview (SSI) with Chinese American parents/caregivers raising an individual with an intellectual and developmental dis/ability throughout Spring 2020. I chose to utilize semi-structured interviews because it allows me to guide participants and probe their responses throughout the interview while allowing flexibility in participant responses because they can open-endedly share stories of their experiences (McIntosh and Morse 2015). This framework also enables participants to navigate the interview in a natural flowing conversational manner, which helps me build up a rapport with them and attempt to make them feel comfortable enough to share their narratives. The interview questions were based on the design of Chen's study that conducted the study with Chinese parents about their perceptions of Autism Spectrum Disorder (Chen 2014). Furthermore, this interview will be a descriptive/interpretive type of SSI with the focus on the participants as the knowers and me, an interviewer, as someone probing their knowledge (McIntosh and Morse 2015). This framework acknowledges the limitations to knowledge and is crucial to extend my understanding through both confirmations and refusal from the participants, in this case, the caregivers. The pliability of their responses also will help me develop my hypothesis, themes, and categorizations to discern and comprehend their experiences (McIntosh and Morse 2015). Furthermore, semi-constructed interviews provide me with some variability in how I ask or rephrase the questions to the participants for clarifications or for drawing out pertinent materials. I have included in my

interview guideline (Appendix) that would expand on the participants' initial responses (McIntosh and Morse 2015).

Sampling

I used convenient sampling to recruit participants who identify as Chinese American caregivers with raising children diagnosed with an intellectual and/or developmental disability through two main networks. First, by contacting physicians from Jefferson Center for Neurodiversity to connect me with potential caregivers of children they work with. Second, through community organizations and institutions that provide resources for Asian American communities and/or families with children with special needs. Through word of mouth and connections from advocates, disability community members, physicians, helped connect me with suitable families that fit the following criteria in their professional and/or social networks:

- 1) Must be at least 18 years old
- 2) Asian American caregiver of a child/individual who is medically diagnosed with Intellectual and/or developmental disability.

There was a total of three caregivers who were interviewed for this study. They were all Chinese American immigrants or children of Chinese immigrants.

It is extremely important to be able to establish a rapport and earn the trust of the potential participants and the community of caregivers ((Hiller and Diluzio 2004). Families may be more inclined to participate in the study with a trusted relationship, understanding of my work, and guaranteed confidentiality. With the limitations of this study, it was a challenge to fully engage in building solid relationships over a long period of time with families and communities and be an ally. I tried to mitigate this by establishing preliminary phone calls with potential participants to explain my project and what prompted me to be interested in conducting

the research. I recognize how sensitive this topic is to many families, and thus, by being transparent with them about the purpose of my study and how it personally related to me I hoped to alleviate some of the participants' reservations and uncertainties. Furthermore, I also conveyed that the interview would last approximately one hour. At one hour, if the individual felt comfortable with continuing with the interview, then we would do so. If the participant had other obligations or would like to stop the interview at the agreed time, we did. Additionally, each participant received a 15-dollar gift card for amazon through the mail.

Below is a short description of each participant, their family demographic, and the services the individual diagnosed with a disability in the family utilize.

All three families – Steve's, Linda's, and Michelle's – shared common backgrounds. Their experiences are not representative of all Asian American caregivers and their experiences. All three families are immigrant families who immigrated to the United States. They moved to America in hopes of a better life for them and their children financially and otherwise. Both parents in each family began in the restaurant business. It is not uncommon for Chinese immigrants to work in the food industry as cooks and waiters due to networks and connections, often through relatives or close friends. All three families have indicated that they all worked within the restaurant business and each family had their restaurant(s) before their child's medical diagnosis.

Steve: Steve is an older brother to Peter, who is now 29 years old diagnosed with down syndrome three months after he was born. Steve's family originally immigrated from Shen Zhen

city in Guang Dong Province to Hong Kong in the 80s and immigrated to the United States by the late 80s. They began in the restaurant business but due to some extreme circumstances, their father switched to work in life insurance. Steve's mother became a full-time stay at home mom to take care of both children. Steve is 31 and has a newborn son and a wife. Peter currently lives at home in Northern Liberties in Philadelphia, PA with his parents in the same apartment complex as Steve's family. Their family lived in the suburbs of Southeast Pennsylvania until about a decade ago when they moved into the apartment complex. In the suburbs, Peter received an IEP education from middle school until high school graduation, after which he participated in a program that taught him how to navigate basic life including going to the bank, doing laundry, etc. He currently has a social service aide who keeps him company during the morning and early afternoon.

Linda: Linda is a wife and a mother of two; a younger son and an older daughter who is a senior in high school. Her younger son, Ron, eight-years-old, was diagnosed with Autism spectrum disorder. Linda and her family immigrated here when Linda was 18 when she immigrated from Changle/Fuzhou area of Fujian Province to the United States. Linda and her husband began in the restaurant business. Linda's family had a restaurant in Philadelphia and husband's family closed theirs in New Jersey and moved to Philadelphia. Linda is a full-time stay at home mother who is very involved in her children's education, advocacy, and parent support groups for parents of children diagnosed with autism. Ron is currently enrolled in an IEP program in a Philadelphia public school. Ron has a one-on-one aide who is to accompany Ron throughout his class days. Other than education services, Ron also had occupational, speech, physical, and cognitive behavioral therapy through multiple Philadelphia medical systems.

Michelle: is a wife and a mother of two sons: the older one, Drew, is 9-year-old was medically diagnosed with Asperger's when he was 5 years old and the younger one, Larry is 5 years old and has a speech impediment and was recently diagnosed with juvenile idiopathic arthritis (JIA). She also immigrated here on her own in her late teens from the Changle/Fuzhou region of Fujian Province in China to New York City, and then to the Philadelphia area. She met her husband and had Drew in the United States. Their family was at the time still financially unstable, and thus Drew lived with his grandparents in China for the first three years of his life. She is currently a full-time mom with a part-time job at Elwyn, an organization based in Delaware County that provides education, treatment, and support services to individuals with IDD and other related behavioral health challenges (About Elwyn 2019), as a parent partner. Drew was formerly enrolled in an IEP program in a Philadelphia public school and now attends a public school in Lower Merion, Pennsylvania in a standard classroom with extra resources. He also utilizes speech therapy and has attended social skills groups. Larry, on the other hand, was utilizing early intervention services at Elwyn and continues to receive speech therapy in Lower Merion. Larry is still receiving interventional and preventative treatment and services from the Children's Hospital of Pennsylvania (CHOP) for his juvenile idiopathic arthritis (JIA).

Linda and Michelle are in the same support group, both of whom are very active in their participation in advocating and aiding other caregivers. The interviews conducted with the participants are split into two languages. English and Mandarin. One was conducted in English, and two were conducted in Mandarin. When I transcribed the Chinese interviews, I transcribed it based on my own interpretation and translation of the Chinese audio clips, and thus they are approximate translations, but some words or context may be lost in translation, affecting the quality possible accuracy of the interpretation.

Data Collection:

The interviews were conducted (Face-to-face)/ (through skype/video/phone calls) etc. The settings of the interviews were selected by the participants including, time, place, and language, to ensure the participants' comfortability and availability (Wang and Casillas 2013). All of the interviews were audio-recorded and transcribed for data analysis. Being cognizant of each participant's time and different needs, as each one of them serve multiple roles within their family, I ensured that I was flexible and able to accommodate them. I gave the participants the choice of conducting the interview in-person or over the phone. They have also requested to have the interviews be in the language that they were most comfortable with, which in this study was Mandarin and English. I conducted an in-person interview with Steve at a place that he chose at the time that he was available. The two other participants, Linda and Michelle, both of whom are full-time mothers and I planned to meet in person individually to conduct the interview. However, due to multiple circumstances, we ultimately decided that the most convenient way to conduct the interview is through the phone. Since both individuals expressed feeling more comfortable being interviewed in Mandarin, I translated my interview guide into Chinese.

During the process of translation, I ensured that the transcription would be culturally appropriate, and to minimize any wording that would directly translate to a harsh tone/inconsiderate tone. I consulted with two Chinese professors, one of whom is well versed in medical/cultural Chinese. We collectively worked to have a copy of a bilingual transcript. This was crucial as I am colloquially fluent in Chinese, but I am unfamiliar with the vocabulary and specific rhetoric used in this context.

The interview questions were focused on asking questions about:

- 1) The child's current well-being and their interpersonal relationship with both family and nonfamily members

- a. *Can you tell me how your child is getting along with their siblings/family member and their peers?*
- 2) Participant's initial and current reactions/perceptions of their child's diagnosed condition
 - a. *What do you think may have caused *the child's name* to have this condition?*
- 3) Support and stressors for the participants
 - a. *Who is your support system in the United States?*
 - b. *Can you share with me some of your fears and anticipations for * the child's name * as they are growing older?*
- 4) Their experience providing care/raising the child
 - a. *Can you share with me what you think has been the hardest part of raising your child? What is the most rewarding part?*
- 5) Participant's interactions and experiences with providers
 - a. *Can you tell me about your experience seeking and receiving medical care for * the child's name *'s condition?*
- 6) The impact on the participant and the family's interpersonal relationships
 - a. *Can you tell me what it was like when you shared the diagnosis with other family members/ closed ones?*

Data Analysis:

All audio-recordings were transcribed for data analysis. To ensure the privacy of the participants and the participant's family, pseudonyms were used. Amazon AWS transcribe was utilized to transcribe the first set of audio recordings with Steve. The files were in .json and through a series of python codes, I converted to a text file that could be read through Microsoft word. Afterward, I went through the recording two more times to ensure that the transcript was accurate. However, due to a multitude of reasons including dialect, method of recording, language, and more, the AWS transcribe could not generate an accurate Chinese transcript from the conversations that I had with Linda and Michelle. As a result, I manually simultaneously

transcribed and translated them from the audio recording from Chinese to English to the best of my abilities.

Then transcripts were all analyzed by manually categorizing the interview data based on reoccurring themes. This method of qualitative analysis is utilized to identify, analyze, and report different themes that were present throughout the data (Braun and Clarke 2006). I read through each transcript multiple times and highlighted/marked content within the transcript that I found to be relevant. Afterward, the content was reviewed to categorize into preliminary themes. These themes kept in mind and refined as I read through the interviews a couple of times, to ultimately generate themes including but not limited to “social barriers”, “medical barriers”, “immigration”, “family dynamic” to name a few (Vaismoradi, Turunen, and Bondas 2013).

Analysis:

As Americans, each family with a child with a disability should have the same access to services available for those who have a form of intellectual or developmental disabilities. The multitude of barriers including structural, financial, cultural, and social, that these caregivers face when they navigate their child's diagnosis and to access crucial resources needed for their child's development was revealed through the interviews with three Chinese American families.

The three Chinese American families are Americanized to an extent. By this I mean they have assimilated to the American culture, learned English, and adapted somewhat to the American family dynamics. They are more independent in childbearing and care than their non-Americanized counterparts (Bui and Turnbull 2003). When I asked Linda about her support system, Linda responded,

In the US, everyone is very busy and is busy individually. Only occasionally we would call on the phone or send a WeChat message to talk. But actual face to face time is very little.

Most of Linda's extended family members live in China while she and her immediate family immigrated to the United States. When they immigrated, their family dynamic shifted. Linda, her sister and parents no longer live together – her sister lives in another state. They each have their own families and jobs. As a result, the only way they connected was through phone calls or WeChat (a popular communication platform for Chinese people).

Similarly, Michelle expressed that

My [her] biological relatives are all in China. My friends are also not around here.

They're in different states. Furthermore, I am the type of person who doesn't like

to ask other people for help... but unless I am in a very desperate situation, I wouldn't reach out to them for help.

Although Michelle's personality partly contributed to her reluctance to reach out for help, another aspect is because she does not have friends or relatives living close to her that she felt comfortable reaching out to after moving to America. The traditional Chinese expectations for family members to be there to support and help one another do not apply to their Chinese American immigrant lifestyle. This finding is consistent with Bui and Turnbull, who found that in recent decades, AAPI immigrants experience shrinking extended family systems as a result of geographical separation. Thus, there is also a curtail of emotional support and economic resources available for families like Linda and Michelle's and especially families children with disabilities (Bui and Turnbull 2003; Zechella and Raval 2016).

The medical diagnoses of their child's condition altered the family dynamics in all three families. Before the diagnosis, both parents in these three Chinese American households contributed to the household income as "dual wage earners" (Glenn 1983). For example, Steve's "parents are like everyone else; they started a restaurant." This quote emphasized how common it was to Steve that Chinese parents often started their careers in restaurants after immigrating to the United States – both of his parents did. Similarly, Linda said,

my family and I immigrated here from Fujian in 96, and my father opened a restaurant here in Philly where I was working in... he [her husband] moved with his family to New Jersey where their restaurant was.

However, after their child's diagnosis, the fathers in all three families continued to work and became the primary breadwinners for their families. On the other hand, these two mothers took

on the caregiver role to accommodate their child/ren's special needs. Both families have an older child who is neurotypical. When they were born, the mothers continued to work. However, after their second child's IDD diagnosis, with Peter having Down syndrome and Ron having ASD, both mothers quit their job to become full-time mothers. In Steve's family,

Dad was the one that went out and got bread, and then mom was everything at home, dad didn't need to think about it or worry.

Likewise, Michelle and her husband:

Close[d] our restaurant because we weren't able to make a lot of money anyway. If we continue on my son would become disabled, and we wouldn't be able to make any money. Everyone's health and well-being would have been negatively affected. From coming out of that business, I became dedicated and seriously partake in providing care for Drew and to understand him... He [husband] does restaurants... He's usually home from Sunday, to Tuesday and the rest of the week he's at work.

Michelle's statement was prefaced with her explaining that she and her husband ran a restaurant that was not doing too well and was in a really bad neighborhood. After school, Drew would be doing his homework at the restaurant with both of his parents. However, with the amount of stimulus and distractions that he experiences there, he was not doing well in school. Thus, Michelle and her husband made the collective decision to close their restaurant. She then became a stay at home mother while the father worked away from home a couple of days a week and came back home Wednesday through Saturday. All three families with dual-parent households ultimately decided that the mother stays at home to take care of the child with special needs, especially after the diagnosis, while the father serves as the breadwinner in the family. The

decision to have the mother stay at home as the caregiver was made without much discussion. They abided by their understanding of the Chinese cultural norms, which in this case was the patriarchal family dynamic (Wang and Casillas 2013; Bui and Turnbull 2003).

The Stress and Reactions of Medical Diagnosis

Most parents experienced a lot of stress, sadness and uncertainty when receiving news from a healthcare professional that their child has lifelong chronic health condition (Lo 2010; Stuart and McGrew 2009). When I asked Linda what her initial reaction to Ron's diagnosis was, she replied:

I was really heart broken and sad. Really heart broken and sad because my child from birth to three years old was a healthy one.

Before Ron was diagnosed with ASD, he did not exhibit any type of physical symptoms that warranted him to have to go to their pediatrician often unlike his sister whom got sick often, with fevers, colds or chills. She did not suspect that there was anything atypical about his development. He was always considered a smart and healthy child. Ron's diagnosis left Linda to mourn the loss of the child that she thought she knew and afraid of the uncertainty of his future.

Steve explained that when Peter was diagnosed with Down syndrome at 3 months old, his mother was also sad. According to Steve:

[My mom] was naturally a little heart broken. You know, you never want to hear anything "negative" about your child.

Throughout Steve's mom's pregnancy with Peter, there was nothing that indicated that Peter had Down syndrome even with amniocentesis. The healthcare professionals who delivered Peter and took care of him never recognized the distinct physical traits of Down syndrome that Peter had

until 3 months after. She was led to believe that her child was healthy and a typically developing child until his diagnosis. She was heartbroken because of the loss of a “normal” family, and because she knew that he would not have a typical childhood like the other children. She grieved, for herself, her family and for Peter’s future.

During our interview, Michelle cried to me when she recalled the day, she received news about her younger child’s JIA diagnosis

They [healthcare professionals] wouldn’t tell me what they were doing to my child or anything. I was really scared on the spot.

Michelle’s fear was dominated by the fear of the unknown about her child’s condition. She had been trying to understand what Larry’s health was like with the limited English and health literacy that she possesses. However, no healthcare professional took the time to explain to her their process and the lab results. She assumed the worst; she was scared that she was going to lose her child. These feelings of stress and sadness are associated with the fact that the mothers have never heard of their child’s condition or how to accommodate them before this diagnosis. Michelle had said,

“I have heard of Autism, but don’t know anything about it... I have never heard of JIA until the pediatric rheumatologist came into the room. I did not know what they needed, I learned how to take care of them day by day.”

Both her children have been diagnosed with a form of disability. Not having heard about their conditions before and with no guidance from professionals, it became her own responsibility to learn how to accommodate their needs. Like Michelle, Linda exclaimed that

“I have never heard of autism before, let alone signs for autism. I couldn’t really accept the fact that he has autism and that autism has a lot of challenges. I didn’t think that there were a lot of challenges”

Linda had not expected that Ron’s Autism was going to have much impact on his life because he appeared to be smarter than his peers ever since a little child. She did not know that having Autism comes with communication barriers between Ron and those around him until the symptoms became more apparent.

Likewise, health and cognitive impairments was stigmatized within these Chinese-American families (Clough, Lee, and Chae 2013). What these mothers knew about their child’s developmental disabilities centered around Chinese rhetoric of disability (*canji* 残疾) (Kohrman 1999) and “mental illnesses” (*jingshenbing*, 精神病) which inherently has a derogatory and negative connotation (Baum 2018). In corroboration with the medical model of understanding disability, their child’s medical diagnosis signifies that there is something inherently wrong with their child’s health (Shyman 2016). Michelle’s family members in China described Drew as:

“having *shenjing bing* 神经病, like my mother who became *dai* “呆” after her brain surgeries.. My sister said that he definitely has a brain disability *nao can* 脑残. He was completely brainless.”

The rhetoric that her family used when describing the atypical development signs that Drew exhibited was negative. Drew was described to be “crazy” or “insane”, “stupid”, “brainless” and “defected brain”. These were colloquial terminologies that continue to persist in talking about mental health and atypical mental conditions.

While Wang and Casillas found that highly educated families from Taiwan and Hong Kong do not experience shame about diagnosis, the families that I interviewed did not mention

feeling ashamed of their child's condition neither. The three families I had interviewed were from mainland China, and none of the parents pursued a higher education (Wang and Casillas 2013). However, the mothers do experience their extended family members blaming them for their child's condition on top of their own guilt. Linda explained that:

My parents-in-law, believed that it was me who harmed Ron and put him in this situation...My in-laws think that I treated my child really badly, like I don't care for my children, and because I allowed him to cry too much, it caused his autism.

Her parents-in-law put blame on Linda and suggested that it was her discipline and neglect that caused Ron's autism and his autistic behaviors (Holroyd 2003; Ghosh and Magana 2009).

Linda's parents in laws blame on Linda for her child's condition further contributed to her stress and sadness. However, Linda did not allow her parents-in laws' words affect how she cares for her child. Linda is cognizant of her efforts to ensure that her child gets the resources that they need and lives a life that is not defined by his disability.

In addition to external blame, the mothers blamed themselves for their child's condition, for not seeking out help earlier, for not recognizing and/or for causing their child's medical condition (Cooc and Yang 2017). For example, Michelle initially believed that

When I was pregnant with Drew, I went to see a dentist... I didn't know that I was pregnant. But my tooth hurt, and so I went to get a root canal and address cavities in my mouth which resulted in changing tooth caps... We used general anesthesia, I think that it might be because of that that he has autism.

Michelle's initial conclusion about the causation of Drew's autism was based on her understanding in her culture that a mother's action during pregnancy will directly impact on the health and development of the child (Ghosh and Magana 2009). In Drew's case, Michelle sought

an external medical factor she believed had caused her child's condition. She initially approached Drew's condition through the medical model of disability, medicalizing his condition as a one caused by a biomedical agent. However, she nevertheless blamed herself for his condition because she could have prevented his Autism (Retief and Letšosa 2018). Michelle was also cognizant and felt guilty about seeking treatment several years after she realized the neurological signs in her child.

When he was younger, he was living in China, but he had these signals already... Drew had similar symptoms that was very similar to my mother's neurological symptoms, I started crying, I have the feeling that he has autism but we did not get an official diagnosis until he was 5 when we actually medically diagnosed him.

Michelle and her family as mentioned previously saw signs in Drew's development that reflected her mother's neurological conditions. Her mother had a stroke and underwent brain surgeries that left her with neurological damages, delayed cognitive processing, and difficulty communicating. Her mother was considered permanently disabled in her brain, or brainless. However, she continued delaying his diagnosis due to barriers that will be mentioned later on in the analysis. It was not until a psychiatrist came to evaluate Drew's cognitive abilities during his transition from an Early intervention program to elementary school that he was formally diagnosed. Peter's mother, Eve also projected the potential cause of her child's condition on herself. Steve expressed that his mother wondered if it was

karma, fate "*yuan fen* 缘分", or predestiny from something she did in her previous life that caused his Down Syndrome.

These mothers' perception on the cause of their child's condition is a direct representation of the social construction of both the stigmas and understanding of intellectual and developmental disabilities (Wang and Casillas 2013; Sage and Jegatheesan 2010).

Parental Experiences Navigating Resources

These families became skilled at providing and adapting to the needs of their children with disabilities at home (Riper 1999), even when they knew little about their child's condition. Steve explained that after the initial shock, their family adapted to Peter's condition and learned to see him like everyone else. Everyone, disabled or not, has limitations:

Everyone has their limitations... we're all different actually. So, it's just another variant of that.

As a family, instead of defining Peter by his congenital condition, his needs, or his physical appearance, his family accepted him for who he was. Rather than confining to the medical model of disability, they normalized his condition and chose to not see him as flawed or limited, just different. The whole family is cognizant of Peter's condition, including Peter, which helped with their temperament and patience with him. They learned to set boundaries on when to intervene in his day-to-day task for his growth.

At home, family members come to adapt and learn what triggers may provoke their child, how to mitigate them, and how they can assist their children in navigating daily tasks. Michelle says:

We just have to give him some reminders or points in terms of helping/supporting... When he [Drew] has negative emotions, because I know him well, we know when he might be starting to have a tantrum, and we would figure out what is bothering him. Then I would help him plan/organize it for him. He

will follow my guidelines... if he is experiencing more pressure, then we wouldn't add extra things for him to do.

Michelle adapted to Drew's needs and learned his body and nonverbal language. She developed her language of care that best suited Drew's needs as she continued to support him through his daily tasks. Caregivers adjusted their expectations, like academic intensity, for their child to fully accept what their child's autism entailed and learn what approaches would be beneficial for growth and future. Ultimately, these parents were all committed to adapting to their child/ren's needs and well-being so that they can be independent, happy, healthy, and hopefully be able to take care of themselves (Wang and Casillas 2013).

Siblings also played a crucial part in caregiving for the individual diagnosed with a disability. They assume their role in the family as a caregiver, role model, and teacher to their sibling with disability (He 2017; Sage and Jegatheesan 2010). Steve expressed that:

As I grew up in high school. Kind of helped out a little bit more sitting in on meetings like IEP meetings ... sometimes for bad behavior... When I was 15,16, I was going to his social security meetings to renew his benefits. They had to do interviews back in the day. I have to sit there as a parent, sibling, brother so.

Steve, as the older sibling, took on multiple caregiver roles including being Peter's closest friend, watching after Peter, and because of Peter's limited speech abilities, translating for Peter. He understood Peter's behaviors and could interpret what Peter's trying to convey. Nevertheless, Steve and Peter's dynamic was reciprocal. Although Steve does assist Peter in communication and administrative work, Peter is a very sociable individual who greets everyone he knows in the building, and Steve would be acknowledged often as Peter's sibling. Peter taught Steve patience,

relaxation, and through Peter, Steve formed friendships with the people that Peter greets.

Likewise, Linda described Candice', Ron's older sister's role in the house:

She is 9 years older than Ron, but she really likes to hold him and show care to him even now that he's 8. Whenever I'm writing an email to the school board, for IEP because I don't understand things, I will ask her... I will tell her what happens with Ron every day, what they did to him in school, and what the emails or notes say about him. She slowly grew with me to understand these problems and now she said that in the future, she wants to become a special education lawyer.

Both Steve and Candice are second-generation Chinese Americans and thus are likely more acculturated with the American society than their parents. As they embrace their caregiver roles in their household, they also fostered a positive relationship with their siblings. As the older sibling to a younger sibling with disabilities, they both serve in the caregiver role by handling the administrative requirements that their parents ask of them. They grow and learn alongside their parents and their younger sibling on how to adapt and display their language of care. Both Candice and Steve formed tight bonds with their younger sibling. Through them, Steve and Candice have reciprocally developed their personalities and their awareness about the disability communities.

Linguistic Barrier

While it is not clear, healthcare professionals may be less inclined to converse and provide education and information about the patients or in this case, parents of these children's health and medication due to the language difference (Clough, Lee, and Chae 2013; Baker et al. 2010b). However, this along with the stigmatization around mental health conditions and the

limited resources that are publicly available in the Chinese community contributed to the caregivers' limited knowledge about what they can do as caregivers, what is best for their child - especially after their child's diagnosis. These limitations further contributed to the delay of the child's care (Wang and Casillas 2013).

Linda expressed that:

They [providers] didn't explain anything. They did invite a translator at that time, I didn't really understand... they asked me questions about my child's growth and development, but the reality is that they didn't really explain autism.

Healthcare providers who provided diagnoses did not take the time to translate nor explain what the implications of the conditions would be, what Ron's future would look like nor what resources or treatment should Ron receive in order to able to optimize his growth and development cognitively, behaviorally, and socially.

Michelle said:

After the diagnosis, they only said after this you must take these medications, and when I should come back for another visit... There was no information about this shot in Chinese, everything was in English... No one came to tell me anything about what types of symptoms would you [I] be expecting and how is life going to be afterward.

These caretakers feel that professionals did not reassure them at all of the uncertainties. The lack of information and preparation as well as their inability to communicate well with their providers left the parents with a lot of uncertainty and unnecessary, undue stress. Their stress could have been alleviated had their providers took the time to translate and elaborate on the implications of being diagnosed with the condition. As mentioned before, the caregivers were not informed of

the therapies and treatments that their child needed nor where they could access these remedies. Their inability to communicate their concerns and questions with their child's providers that they have about their child's diagnosis left them frustrated and hopeless (Clough, Lee, and Chae 2013). For example, When Larry was hospitalized at Main Line Hospital for a fever, many residents, nurses, and attendings that walked in and out of his room and ran tests on him. The test confirmed an infection, but the health professionals were unsure where. When conversing with Michelle during the interview, she became angered as described her experience:

they [healthcare professionals] kept on saying the word meningitis...I didn't really know what they were saying, there was no one there who was willing to translate what they were saying/discussing to me. I was observing their facial expression and body language and I was guessing myself."

Healthcare professionals at Main Line did not have any explanation for Larry's symptoms. They suspected that it was meningitis. None of them took the time to translate and explain to Michelle what their current suspicions of his conditions were. With Michelle's limited English proficiency, she was able to understand some words that they said, specifically the word meningitis. The rest, she observed their body language. She assumed that they believe Larry has meningitis and began researching about it online herself. A language barrier increases the likelihood of misdiagnosis, misinformation, and miscommunication. Although many institutions have begun to employ translators, whether in-person or virtually, to mediate conversations between parents and providers, the services may not be reliably available, and words may be lost in translation. This may lead to parents feeling confused, frustrated, angry, and powerless (Bui and Turnbull 2003; Fox, Thayer, and Wadhwa 2017). This is what occurred when Larry was transferred to CHOP for care. Michelle continued:

Do I have to ask them [doctors] one by one? And then later there was a doctor who came over and was on the phone and overheard. He knew that I knew how to speak Chinese and a bit of English, so he came over and said, based on his results, there is no specific place in his body that has an infection, but his WBC count is still high.

Although many providers came in and out of the room, no providers thought to use the translator service that was available in person or on the phone to communicate the test results to Michelle and her family. Michelle consistently went around trying to ask the doctors what the situation with her son was. She cried on the phone with me as she recalled this scenario and how frustrated she was at her doctors for not providing her the information about her child that she pleaded for. When Linda tried to explain to the educational team in charge of Ron's IEP care that they have not been following IEP based protocols, she also expressed similar frustration and hopelessness.

I was really upset because these were written in the plan [IEP] for 3 years... If Ron is not within your eyesight you call the office immediately, go to the alarm, and find Ron... Even though my [her] English is not good, I was still able to translate and point to it [safety protocols] on the plan... If you don't look at it, 10 plans wouldn't even be useful... But they don't even care about my child... As a parent, I felt like I had no power.

After Linda found out about the incident of Ron going missing, she confronted the educational board, who dismissed her readily because she could not properly advocate on his behalf during the meeting. Language barriers between professionals and caregivers caused inconveniences and

additional stress on these parents and further discourage them from seeking resources (Keyes and Owens-Johnson 2003).

When there are translators available, even for the difficult specific dialects, parents' limited English proficiency and health literacy may be exacerbated by the poor quality of the translation service. This might result in poor quality of care. (Clough, Lee, and Chae 2013). Both Michelle and Linda were required to fill out a long checklist/questionnaire, which was inaccessible to them due to its language. Michelle recalled:

The ways in which the questions were phrased, they phrased the same question in many different forms, it's all about the same, but they're not easy to understand.

Because they aren't easy to understand I only completed half of it in the past. I even had a social worker help me fill it out, but never gave it back.

Furthermore, when providers converse with these parents who have limited knowledge about their child's condition, the parents do not understand the technical terminologies used by professionals. This creates additional obstacles to fully access necessary care for their children (He 2017). The inaccessible language that providers utilize with parents, even if it's through translators, left parents confused, angry, and helpless because they could not understand. When Linda received the results for Ron's autism consult:

“They did not really explain autism, and when they look at the test results (lab reports), they will just read off of the lab report to me. I don't understand what the contents of those lab reports are, I don't understand those numbers. And they were all in English.

Likewise, Michelle disclosed that:

“They [doctors] kept saying that my child’s WBC counts are really high... But they didn’t tell me that that was a sign that there’s an infection in his body. Okay, we didn’t know what it meant, so we just thought his WBC was high right? ... We went to ask the doctors, and I started to think and ask high WBC does that mean he has an infection? Do you[doctors] know where the infection is?”

Michelle and Linda did not understand what the labs and numbers indicated, whether they were in Chinese or in English. This insidious cycle of them not understanding the information they were presented with and the professionals' lack of effort to communicate what they know about their children contribute to both of their stress and frustration.

As a result, the lack of information and resources available to caregivers is in part due to the healthcare providers’ lack of translation services and communication with the caregivers. Caregivers are not well-informed of their rights, the resources available for their children and are unfamiliar with the system i.e. education, social work, and Medicare that are specifically catered to individuals with disabilities (Wang and Casillas 2013). For minority parents with limited English proficiency, the accumulation of both linguistic barriers, the English language, and the technical terminologies, reinforce the power dynamic that providers already exert on these vulnerable parents. These are the very parents who have/had been experiencing other forms of challenges to obtaining care for their child/ren with disabilities.

Culturally (in)Sensitivity

Linguistic barriers aside, the lack of culturally relevant resources for parents with children diagnosed with IDD exacerbates the inefficient care provided to minority parents. When Peter was diagnosed with Down syndrome, Eve did not find out about special education and IEP

programming for individuals with Down Syndrome and other special needs until they moved to another suburb of Pennsylvania.

I guess in the suburbs, they just had these schooling services there... provides a service and people to help direct those services and make it apparent. We eventually got in touch with these social workers and then they placed Peter in a daycare set up of sorts. Eventually, he went to Middle school, where he really got a taste of an IEP based class setting with programs and teachers with experience with kids with down syndrome and other disabilities.

It was by chance that they met someone in their new neighborhood that was able to direct them to the right resources to ultimately place Peter in an IEP program with professionals trained in working with individuals with special needs. The fact that none of the social service workers the family worked with throughout Peter's childhood recommended or referred them to enroll Peter in special education programs could have potentially delayed his cognitive and linguistic developments. Although legislation and policy regulations for equitable access to disability needs, like special education, have been established for decades, not all professionals in the United States are trained to be equipped to accommodate limited English language speaking professionals (Baker et al. 2010b; Connor and Ferri 2013; Grossberg 2011).

All three families have also agreed that the forms and resource pamphlets they receive should be translated to both simplified and traditional Chinese for Chinese families in an accessible language. As mentioned above, when Michelle was filling out questionnaires in the diagnostic process for Drew, she could not understand the content and even needed a social worker to help with the form. Ultimately, she did not end up turning the questionnaire in. She requested that:

these forms can be changed/ or translated to Chinese, or to a Chinese that we can understand it would make it much easier for us. But it's not the google translated Chinese because there's a really big difference in google translation and the actual meaning.

She hoped that the questionnaires and resources they receive could be written in a way that is more accessible for the general public instead of utilizing technical terminologies.

Furthermore, these parents expressed a lot of discontent for the lack of sensitivity and compassion from professionals' dismissive attitudes (Jegatheesan 2009). When Larry was hospitalized for his JIA, Michelle asked questions and conveyed her worries with his rheumatologist through a translator.

The translator would not be willing to translate the words that I was saying, so I asked what types of symptoms and resources he needs, and when these symptoms flare-up. And basically, if he will die. The doctor said, 'you should save money for him to go to college'. That's how he answered me.

Michelle was trying to understand what the worst-case scenario would be, and how she should prepare. Instead, she was dismissed. She was also reminded of the time when Drew was diagnosed with autism.

When we went to get evaluated for autism, the doctor said that he's going to be okay and that he'd be able to go to college, etc. But they didn't tell you how many individuals with autism don't actually end up going to college. How many people cannot live independently?

Michelle was confronted by apathetic attitudes of dismissal from the professionals that she had encountered in the medical systems for the care of both her children.

Similarly, Linda voiced her personal experience with the educational system that disregarded her concerns, was condescending, and suggested blame on her family. Ron's Autism diagnosis met the eligibility requirement for a one-on-one aide. However, Linda said that these aides have never abided by the IEP. When she raised the concern:

They [school] described it as Ron's fault for not complying... The one-on-one aides are from outside agencies. Because the aide was a contracted one-on-one, the educational department replied that they have no ability to force them [aides] to do anything. I was really upset... My child should have a standard of education that follows the IEP... I asked why can't you [the school] change the individual to be people from the educational departments with extensive training... But they won't change.

The school responded to Linda's concern with an apathetic disregard with the excuse that they did not have the ability to force the school aides contracted into their education system to do anything. Moreover, the school blamed Ron for not complying behaviorally. Such behaviors from the school deviate from the PCP IEP, thus contributing to Ron's delayed development (Keyes and Owens-Johnson 2003).

The parent-professional relationship that was strained by the school board's inadequate response was fractured by their incompetent actions. Linda described the time that:

This year in September, Ron's arm was harmed. It looked like someone forcefully pinched him, like he was to walk but someone grabbed him really hard. It's a handprint outlined bruise on his arm. He was wearing a T-shirt, so when I asked him to wash his hands, I immediately sent an email with Candice, to the school asking why there's a bruise on his hand, the Principal responded with I don't

know. The second day, they [school representative] said that Ron probably did it to himself... I asked them for an investigation, but I don't think that they actually did it... The liaison said that he probably did it at home. When I raised my concern, you [the school] blamed it on me. Why would I tell you [the school] if I did it? I was really mad.

At that point, Linda felt that the school professionals collectively accused her for his bruises. They did not acknowledge Linda's concerns about her child's safety. This was especially troubling because of Ron's Autism

Ron doesn't know how to hate or dislike other people. If someone hurts him, he would forget it in a bit. Because of this, the school thinks that he's very easy to bully/push around because he doesn't understand how to stand up for himself and say that someone is hurting him.

To address the school's incompetent responses, Linda and an English-speaking Autism advocate went to the district board to raise their concerns. When they had done so, Ron's school responded with:

your child does not fit this place [our school]" and had implicated that they should look for other schools.

Such (in)actions taken by Ron's school are representative of the lack of support that some minority mothers may have experienced when advocating for resources that they have the right to. The result of this is another layer of barrier that resource-limited parents encounter when navigating the system. Cultural sensitivity implies acknowledging that both cultural similarities and differences exist without ascribing any to be more superior or inferior than another (Anderson and Fenichel 1989). Just, different. Providers should not utilize cultural, ethnic, or

language differences as their reasonings for dismissing caregivers' concerns like that of Linda and Michelle, nor denying resources and/or services (Keyes and Owens-Johnson 2003; Callicott 2003).

Structural Barriers

Regulations and procedures are instilled within the American healthcare, social, and education systems to reinforce boundaries and control the finite resources available for those who require them. However, these mechanisms present additional barriers for minority folks from locating and utilizing such services (Baker et al. 2010b). Michelle's second son, Larry, has a biting-like sound whenever he speaks, and he cannot enunciate clearly enough for some people to understand. Having experience obtaining speech therapy for Drew, she knew where to seek treatment for Larry. Larry obtained early intervention therapy at Elwyn and CHOP until he aged out at 3 years old. At that time;

In Philadelphia, that's not something they would do. They would just say it's okay... Before he was 3 years old, service was easier to obtain. We were able to get speech therapy once a week. And then, after he was 3, they were unwilling to give that service to us. We went to Elwyn and CHOP for consultation and they said that there's no problem, it's normal, it's just a bilingual condition.

Abiding by the medical model of disability, the Philadelphia public school system denied Larry speech therapy because he was not medically diagnosed with a speech impediment condition, although he still had the speech problem. Instead, the consultants continuously exhibited insensitive and dismissive behaviors; they blamed Larry for being bilingual. Larry's ability to access speech therapy depended solely on the medical diagnosis from the speech consultants. Without the diagnosis, he was not granted the therapy that he needed. His situation is an example

of how a demonstration of the medicalization of conditions like speech impediment provides legal access to resources for individuals with disabilities (Shyman 2016),

Regulations and procedures also cause delays in diagnosis including dispersive services, inability to obtain services, extensive paperwork, and wait times just to name a few. In the discussion about linguistic barriers, we elaborated on the required procedure of having to fill out paperwork for both Linda and Michelle's children to receive a diagnosis that ultimately delayed their child's Autism diagnosis. More specifically Michelle stated that when she reached out for a consultation,

I actually never completed the autism consultation checklists and questionnaires.

There many of them... I only completed half of them in the past. I even hired a social services individual to help with filling out the questionnaires, but I still never gave it back to get an official consultation... When he was 3, we saw the family doctor who referred me for Autism consultation... He was 5 years old when we actually medically diagnosed him as having autism.

She reached out for consultation but could not complete the mandated paperwork for a diagnosis even with the help of a social service worker. The consultation was extremely long, repetitive, and in written in technical terms that discouraged her from finishing it. By then, she already came to her conclusion that Drew has Autism. However, it was not until two years later when Drew underwent the routine psychological evaluation for children in Early intervention programs to transition into an elementary school that he was medically diagnosed. The procedure here posed both as a barrier and a stimulus for the child's eventual diagnosis. On the other hand, Linda said she had to make appointments with multiple institutions by herself after she consulted with Ron's physician:

I had to schedule appointments at CHOPs to do speech consultation, like Autism consultation and at the Center for Autism... I was surfing through both Chinese and English websites to try to learn myself and that was how I learned that he needed OT and PT and fully understand these issues/situations... The OT, PT, and speech therapy that I found, our insurance needed a referral, and that was when I asked my family doctor for a referral. It's not like they automatically gave me any of these referrals.

Making these appointments was difficult due to her limited English proficiency. She also had to research treatments that would be beneficial for individuals with Autism and where to obtain them on her own. In addition to that, the insurance's physician referral requirement was a structural impediment to Ron's care. The lack of both coordination and integration of services provided by organizations further complicated the already difficult and ineffective care system (Khanlou et al. 2017).

Caregivers also highlighted the lack of consistent financial aid and service provision. Although they were entitled by law to receive public services like IEP service, speech therapy, occupational therapy, social security, their care consistently fell short of that expectation. (Khanlou et al. 2017). Steve and I discussed the frequent turnover of social service workers that were assigned to work with Peter throughout his time in school and throughout his adulthood.

Inherently the system regardless of the language barrier, there's a big issue in the overturn in the social service sector. He sees a social service worker every six months for IEP back in the day and probably once a year at this point... Now social service appoints somebody to come during the morning, to take him out for about 3/4/5 hours a day. The lady before took him to Eagle Stadium, then another

now hangs out with him in the morning. There's been multiple of them over the course of the years.

This inconsistency forced Peter to have to frequently acquaint himself with new workers every time. If each family had a consistent service provider, it would promote efficiency in delivering care (McManus et al. 2011). Rather than having each worker familiarize themselves with Peter's situation, they could have spent that time making progress. Linda had also described that Ron had multiple one-on-one aides that were assigned to provide him care.

He will run there and because of his attention problem, so he has a 1 to 1 aid following him. However, 1 on 1 aid turn over, from kindergarten to now has changed a lot. There was one that we really liked, who was with Ron for 1 year and cared for Ron. We were happy that they were Ron's 1 on 1 but they had a promotion and left. And then afterward there were many other aides who never followed the IEP. This November Ron had this new aide, although he was a new aide, he has followed another student before. The one on one aide was not attentive to Ron at all.

However, she was dissatisfied with many of them, as with the high turnover, the aides were not familiar with Ron's IEP and his needs. Much time was spent on trying to learn about rather than furthering his development. Already mentioned before was Larry's ineligibility for speech therapy after the age of 3, which also hindered his speech development. In addition to that, Michelle had expressed that when Larry was hospitalized, there were countless numbers of healthcare workers that were going in and out of his room and drawing lab tests. Yet, no one had taken the time to explain the results to her. The lack of centralized and consistent providers in these organizations provided inefficient and inadequate care for the three families. The

inconsistency of care and high turnover rate that were raised with these three families are the results of the lack of institutional aid and investment and the lowly paid social service providers and educational one-on-one aides.

Racial/Socioeconomic Barriers:

The challenges of racial and socioeconomic barriers - all of which are intertwined - manifest itself geographically (Zechella and Raval 2016). Above, I described the challenges that Michelle and Linda encountered when advocating for their children's needs in the Philadelphia public education system. At the time, Michelle lived in South Philadelphia and Linda lived around Chinatown, Philadelphia. Two different schools, both located within Philadelphia, were limited in their ability to provide quality resources for children with special needs. Michelle said:

We always had this [speech therapy] history. They wouldn't easily give Larry twice a week therapy. But because they saw all of the struggles and experiences, his struggle is still there, and his speech situation still persists. Tones are off and did not improve. They believed me and agreed that he would continue to progress if there are language teachers...the school district [Lower Merion] was willing to provide him with resources. But that doesn't happen in Philly.

As a result, she and her family moved to Lower Merion district near Saint Joseph University. There, Larry and Drew were both able to receive "better services" than in Philadelphia. This may very well be because Lower Merion is a predominantly White, upper-middle-class township. The median household income for Lower Merion Township is \$131,556 (in 2018 dollars) more than double, almost triple, the median household income of the United States. The median value of the owner-occupied housing units is at \$590,000, which is also more than double the median value for the rest of the United States. Thus, Lower Merion township is one of the most well-

funded school systems because of their upper-middle-income residents. Likewise, these residents would demand the best resources and care they may feel entitled to since they pay taxes to the township. Michelle had done her research before their move. She explained that,

White people, they have more resources to share with you, and here, I was able to experience it... This school district, they have meetings with special education families.

The inequity and disproportionality of resources that Michelle's children received in the two districts speak volumes about the relationship between race and socioeconomic statuses and access to quality education. It allows for consideration of institutional racism and socioeconomic inequality that may have reinforced institutional responses to minorities and the resources available in urban areas versus suburban white neighborhoods (Sullivan and Artiles 2011). Similarly, Steve and Peter grew up in the suburbs of Bucks County, a predominantly white county as well, before they moved into Northern Liberties, Philadelphia a decade ago.

The program and teachers were experienced with kids with Down Syndrome and other disabilities. For the first ten years, we were on our own a little bit... After, he was able to finally have a vocabulary and express himself. That was probably when he was 12/13.”

It was by chance that they met an individual who directed their family towards social services. Social service workers placed Peter into a childcare service within a day of being contacted and were then enrolled in the middle school with special needs programs. It was the first IEP based set class setting for Peter.

There is a multitude of layers to uncover in Peter's path to special education. First is the lack of awareness of resources Peter was eligible for after his diagnosis at three months until he

was 12/13 years old. Such a gap in knowledge may be attributed to some part, the limited social network within the disability community which may be potentially attributed to the family's linguistic and socioeconomic challenges in a white-dominated, well-funded county (Baker et al. 2010b). However, another layer is the inconsistency, and lack of coordination with his social service and medical service workers that should have connected them to the necessary resources needed for Peter's development. Such barriers ultimately contributed to Peter's delay to education, and the missed opportunity to provide both Peter and his family with resources and training in his younger years with Early intervention services. Early intervention services would have benefitted the family as a whole, including support, encouragement, and information for the family members and developing and mastering skills like speech and social interactions for Peter (Early Intervention 2010). However, their residence in a predominantly upper- and middle-class county somewhat benefited them in accessing quality and experienced educational resources for the family that Michelle and Linda struggled to obtain in Philadelphia. This disproportionality in resource access may be attributed to awareness, acceptance of intellectual and developmental disabilities, the resources available in the school district, and the sociodemographic of the community.

Linda's continued struggle with the Philadelphia school district resulted in their eventual suggestion for her to find another school that would be "better suited" for Ron. Such actions taken by the institution highlights the low quality of special education that that institution provides. Linda explained:

now the district educational board is pressuring me to leave Ron in the public-school system, but they don't even care about my child's individual needs, they just don't let us go to private school because they do not want to pay.

Although it is not clear, there is a possibility that the district might not be pressuring middle-class white families the same way that they are manipulating Linda, an immigrant parent. Linda took the complaint to higher-level officials in hopes that the district school board would fund their educational expenses in a private school dedicated to individuals with intellectual and developmental disabilities after touring the options suggested by Ron's school and Linda's research. However, Linda also said,

The public-school system refused to pay for my child's education. They don't even care about my child's individual needs". They don't care and I was really upset. As a parent, I felt like I had no power and the school district felt like it's a big team... you have to listen to them

Linda's frustration is very much directed at the broader systemic and structural barriers in place for low-income minorities with limited resources. Other than herself, her daughter, and another parent with children with autism, she was on her own. No social worker advocated on her and Ron's behalf. The school's attempt to address her concerns were haphazard, apathetic, and dismissive. Their encounter with the education system underlines the present disparity in access to quality education for low-income immigrant families with children with a disability. It also reinforces McManus's statement that children from minority races experience greater unmet needs and difficulty gaining access and negotiating with institutions including Social service, healthcare and education. As a result, it causes more caregiver burden (McManus et al. 2011). I quote something that Steve said that stuck with me – "Money does wonders, right."

Support Systems

Mothers also took initiatives on their own to seek out resources that they think are best for their children even with limited directions and a language constraint. Linda explained that her

interactions with physicians were uninformative. They did not provide information to the full range of services available to him.

They [healthcare professionals] did not say anything about OT (occupational Therapy) PT (Physical Therapy) related stuff... When we went to the Chinatown Clinic, they also didn't tell me anything about children with Autism needing OT, PT, or CBT (Cognitive behavioral therapy) I found them [these resources] myself.

Ron's providers gave his mother website links and company numbers, but they were not explicit on what care Autistic children need to further their development, and thus she had to find these services herself and independently asked Ron's physicians for referrals for these programs.

These Chinese American immigrant mothers who are providing care for their children with disabilities may feel a lack of support and feeling of isolation. Their feelings may be due to a multitude of factors, including the shift in the family dynamic as previously discussed, privacy, fear of stigmatization, lack of knowledge of support groups as well as linguistic and cultural differences (He 2017; Zechella and Raval 2016). Michelle explained that:

when I come to participate in the workshops in this school district [Lower Merion] on Saturdays, no one actually cares or even acknowledges me. I am the only Chinese person there... However, they would never share their resources, about what information and resources that they have received in the school district. When I go to participate in school meetings, there are mostly just white people. When you go in, you put down your email and at times they will send some email about what type of activities and programming will be coming this month.

When she attended the special needs parenting workshops hosted in the Lower Merion school district, she felt unacknowledged and uncared for by the other participants. She did not connect with any of them as a woman of color with limited English skills. After feeling so ostracized, she said to me:

This is not my country, not my land

She felt neglected by the system that she knew little about and by the people in her residential community. She was hoping to find support. Support groups are beneficial to families with child(ren) with disabilities because they equip them with resources to be their child(ren)'s, advocate. A support group is supposed to be a place that provides support, improve their parenting skills, attitudes, and communication. Furthermore, it gives them a space to share knowledge and skills to cope with their children's special needs (Lo 2010).

These similar experiences gathered Michelle Linda and Allison, a Taiwanese American mother with two children with Autism, to collectively start a parent-led support group around 2014/2015 in Philadelphia Chinatown. In collaboration with medical institutions, Chinese associations, and trusted professionals, they coordinated and hosted workshops for Chinese American parents with children with special needs. Linda said:

We decided that we should do this every month so that the information, so that we can help more families and provide free education and/support for the adults.

These workshops provided Chinese American parents with disabilities education and support about their rights, the resources available, and tips on how to navigate the complex systems of institutions. To be inclusive of all Chinese American caregivers, especially those who speak different dialects, having a platform where the information can be written into the standardized written Chinese form of simplified and traditional Chinese was critical. Linda continued:

I asked if we should make a WeChat group, especially for those who speak Chinese with children with special needs and add them to the group. And slowly, we started from a WeChat group of 3-4 people to now about more than 70 people.

Most of these families were in Philly or in the suburban areas.

Their plan to begin a WeChat group (a popular communication platform) now serves over 70 Chinese American/immigrant families within the Greater Philadelphia Area. In the group chat, they share resources, tips, and difficulties that they encountered. They share linguistically accessible resources and also videotaped workshops if parents could not attend. Such a support group provided these parents with a sense of belonging through new friendships and social networks (Lo 2010).

Conclusion

What stuck with me the most through the interviews were Michelle's words: "This is not my country; this is not my land." Her words reflect some of the ostracization and challenges that these three Chinese American caregivers have continually faced in the process of advocating and obtaining care for their children with IDD. It highlights the reality that with even legislations and systems that are supposed to provide equal resources to all American families, not every family has the same opportunities to access them. As a Chinese American immigrant family with children with IDD, their understanding of their child's condition, knowledge about resources available, and their access to care are heavily influenced by the intersectionality of their identities. Their identities play a factor in where they live, how they are treated, and what treatments and resources they can obtain and utilize. Amongst the three families, we learned that parents in Chinese American immigrant families were all dual-wage earners before their child's diagnosis. When their child's conditions were diagnosed, all three families decided that it was a mothers' familial duty to provide care and accommodate the special needs that the child with disabilities have. They become full-time mothers, primary caregiver, and must navigate the foreign healthcare and social system alone for their child's care.

These experiences also highlight that the medicalization of the child's condition in the Western biomedical context influenced the parents to adopt the medical model of disability instead of blaming themselves or being blamed by others for causing the condition (Shyman 2016; Retief and Letšosa 2018). The mothers have shifted their mentality about their causation of their child's condition to embody the biomedical definition and causation. They understood to some extent, that their child's condition was not their fault, and that they have been doing to the best of their capabilities to ensure that their child can obtain the best quality of care and

education. The diagnosis of their child's condition also opened up resources that are available for these families to help their child; these include vocational therapy, one-on-one aide, and is eligible for other programming specific to the individuals with special needs. We also saw that without a formal diagnosis of a child's condition like in Larry's case, his speech abilities were anomalous from typical speech patterns, was unable to access the speech therapy that Michelle continuously sought out because she thought that the therapy was needed for her child's development. Thus, in this case, the diagnosis from physicians served as the gatekeepers to resources that were made available to them by the state and institutions (Shyman 2016; Conrad 1992b).

Nevertheless, Steve, Linda, and Michelle's families have all endured to multiple occasions of negative experiences interacting with the medical, education, and social welfare system in the United States. Their experiences brought us insight into their family dynamics, mothers' guilt and explored the multitude and combinations of problems and barriers that shaped these Chinese American caregivers' experiences in obtaining care for their child/ren with special needs. We come to understand the emotions of frustrations these caregivers have described when their providers were dismissive, inattentive, and insensitive to the needs and requests of parents. It also became apparent how the intersectionality of their Chinese identity, American identity, and immigrant identity shaped their experience. Their health literacy, language proficiency, regulations and procedures, geographical, and socioeconomic factors collectively halted caregivers from attaining the necessary care for their child within a reasonable time. It also displayed the disparities and the quality of resources that are available to families that live in predominantly White suburbs and within the metropolitan areas. Support groups have been formed amongst some Chinese-American families to connect and provide resources for one

another in an attempt to bridge the gap in resources made available to minority families (Cooc and Yang 2017). As Chinese American caregivers form communities and leverage their resources, it is also crucial for the medical communities, government agencies, and policymakers to prioritize the voices and needs that these caregivers have.

Through this research, we were able to obtain narratives from Chinese American caregivers about their experiences trying to navigate multiple institutions to obtain care for their child and the multitude of barriers they faced throughout the process. Through the interview, caregivers have also personally expressed to me how they believe the institutions and legislation can be amended to accommodate the needs of families like theirs and other families whose identities influence their knowledge and ability to communicate or access care. Steve said, “Social service is medical service”. His statement garnered my attention. He emphasized that aspects of treatments and interventions like being provided social welfare workers and aides who can assist the family and the individual with disabilities with aspects of their life, especially managing chronic health conditions, help to prevent caregiver burnout as well as positively influence the lives and behavioral choices that the family and/or the individual make and need. They are also able to connect caregivers and their clients to appropriate providers and professionals when appropriate because the services would best benefit the client. Such services include psychological services or routine physical care with physicians who the social worker knows are equipped to work with individuals with special needs and can adapt to the cultural and linguistic needs of the family. If implemented correctly, it may improve services and experience of transitioning into the adult care system for youths with disabilities as well as improved services and health promotion. It may ultimately create a foundation for a positive environment,

increased disability awareness for caregivers and individuals with IDD and in the clinical and public health workforce (Krahn, Walker, and Correa-De-Araujo 2015).

Steve also suggested that the governmental agencies, institutions, and investors must connect with caregivers and other individuals within the disabilities community to understand the current situation in their community and where the money should be allocated to best serve families and people with disabilities (PWD). An area that Steve believes needs more funding is the salary for health and social service workers. There is currently a social worker shortage in America with an increasing need for social workers. Insufficient funding may delay diagnosis and/or care for individuals with disabilities which, as we had mentioned, may ultimately contribute to preventable conditions (Social Work Policy Institute 2011). Linda had also expressed that there is a high turnover rate for the one-on-one aides that Ron has due to their low pay and high burnout rate. As a result, by incentivizing individuals to specialize in Social Work and intellectual and developmental disabilities through pay and subsidizing their education may address this concern. However, it is also extremely crucial in all three caretakers' perspectives to ensure that these social workers are well trained, committed, and culturally competent in multiple fields including mental health, health care, education, and working with PWD (Social Work Policy Institute 2011).

Michelle and Linda both advocated for social workers who are well trained, committed, culturally competent, and patient. Michelle suggested that to ensure that health and human service professionals are well trained and equipped to work with individuals with disabilities, there must be annual training for these workers. These workers must have sensitivity training and experiences working with families from diverse backgrounds. The training should be designed in

a way that encourages further dialogue every year so that they continue to gain knowledge and awareness on efficient techniques to work with PWD. Linda and Michelle complained that the current language services in medical settings provide:

“really bad language translation services, whether it’s at CHOP or school, and sometimes they even change a lot of parents’ words or the providers’ words and then communicate it to the parents. This causes a lot of incorrect information and results in miscommunication and misinformation amongst the teachers, school systems, parents, and other professionals”.

To prevent or to mediate their negative experiences with having miscommunications due to their limited English language proficiency, having language services, or having professionals who are trained and well-equipped to relay language services to families/caregivers who have limited to no English language proficiency is extremely crucial. This helps to ensure accurate and well-interpreted communication that is culturally sensitive and is being conveyed to caregivers, especially social workers who are culturally competent and sensitive to diverse cultural and social backgrounds. Additionally, professionals should be cognizant of families or caretakers who have different language competencies so that they can deliver resources and programming in terms and languages that the caretakers can understand. Thus, it is not just about handing out the pamphlet to caregivers, but also to ensure that caregivers understand the content and resources they are entitled to or that are offered.

In addition to ensuring accurate communication between families/PWD and professionals, it is pertinent to have professionals who are committed to providing services for the communities. These commitments include having a personable attitude and patience when

working with these families so that the families do not feel overwhelmed, neglected or dismissed when attempting to navigate resources the way that Linda felt dismissed by the Philadelphia education system. These professionals are there to support, provide, and direct caregivers' resources. They are also there to inform and to protect the rights of the caregivers and PWD that they are entitled to. Professionals like social workers should also ensure that referrals made by physicians or other professionals are being followed up with. At times, children and individuals with disabilities are undiagnosed or diagnosed later in life due to this lack of follow up. Professionals working with families and PWD can help bridge minority communities and essential resources to increase early intervention and diagnosis in children with disabilities. Relationship between caregiver and professionals are extremely crucial in the development of children with intellectual and developmental disabilities.

There are myriads of changes that can be made to the current system to improve the experiences of caretakers from culturally diverse backgrounds through systemic, institutional, and legislative changes. However, this research project focused specifically on the Chinese American caregiver's experience. I hope that this research becomes one of the primary steps in encouraging professionals, including healthcare workers, advocates, academic professionals to recognize that communities with disabilities and minority/low-income families (or families who identify with multiple marginalized identities) face an increased number of barriers when attempting to access care for their child with disabilities. I hope that the work done here can be elaborated into incorporating diverse minority families to document and understand their unique experiences being raised or taking care of a child in the United States rather than relying or basing current policies on research done on White middle-class families and assuming that every

community would need the same type and quality of care that the white middle class family received.

Limitations

There are many limitations due to the sensitivity of this study. The recruitment of participants was through physicians and community leaders with personal interactions with the participants. Due to the limited network and connections that I had, I was only able to recruit three caregivers with children/children diagnosed with an intellectual and/or developmental disability. Thus, the only IDD that was discussed, are Down Syndrome, Autism Spectrum Disorder, and Juvenile Idiopathic Arthritis. Participants also hold different beliefs; have different cultural and familial influences due to their varying levels of education, language skills because of their varying degrees of assimilation to the American culture and years of residence in the States. All three participants are Chinese-Americans. The participants also come from relatively similar financial backgrounds, and their children all have health insurance. Moreover, these individuals are also caregivers that are advocates for their child's condition. One participant partook in a camp that focused on a specific condition with the individual with conditions. This study is not designed to be representative of the whole Chinese American community, nor the Asian American community as it is a qualitative study.

Key Terms

Intellectual and developmental disabilities (IDD): According to National Institute of Health (NIH) is defined as disorders which may negatively affect the trajectories of one's physical, intellectual and or emotional developments only present at birth. These disabilities are often lifelong disabilities that exhibit characteristics of trouble with learning, problem solving, reasoning, adaptive behaviors and more (NIH 2016). Additionally, American Association on Intellectual and Developmental Disabilities (AAIDD) defined developmental disabilities as an umbrella term that encompasses intellectual disabilities as well as other conditions, often physical, that results in a disability including cerebral palsy, epilepsy, down syndrome and more (AAIDD n.d.).

Asian Americans and Pacific Islanders (AAPI)s: The Office of Management in the United States categorized persons into 5 racial/ethnic categories, white, black, Hispanic, American Indian or Alaska Native and Asian (Asian American). Based on their definition, the technical, and politicized term, Asian Americans, refers to US citizens and permanent residents who are of Asian descent (Chen and Hawks 1995). Additionally, this paper will also include those who are mixed race and those who self-identify as Asian or Pacific islanders. AAPI include but not limited to those who classify themselves as "Asian Indians, Cambodian, Chinese, Filipino, Hmong, Japanese, Korean, Laotian, Thai, Vietnamese" Malaysian, and more.

Appendix: Interview Guide

Thank you for agreeing to participate in my thesis project. Your insight throughout our conversations will help me learn more about how Asian-American parents and caregiver's experience and navigate their loved one's medical diagnosis of a condition that would be considered an intellectual and developmental disability. By learning about your experiences, I hope to be able to **inform my knowledge**, and potentially others, especially those working within the medical field to ultimately provide better services and resources for Asian American families. Although, I am aware of the fact that I currently do not have a lot of resources and power to make a big change, I will dedicate my life to advocating and providing services for minorities and those with different capabilities to ensure that they receive equitable care.

感谢您同意参与我的论文项目，您的意见会帮助我更加了解亚裔父母和看护人抚养孩子的经历，并帮助他们对患有智力和发育障碍的孩子及早做出医疗诊断。通过了解您的经历，我希望能_____? **inform myself**----并能告知其他人员，尤其是医疗人员们，最终为亚裔美国家庭提供更好的服务和资源。虽然我明白我现在没有什么能力能做出很大的改变，不过我会致力提倡少数民族和弱势族群的权利....

I will be asking you a series of questions related to your experiences with raising (name of child). I will also ask about your/your family's understanding on the causes of their conditions, your experiences obtaining administrative documents, resources, medical and educational services, your perceptions on the medical care that you receive and your input on what should change within the American systems.

我会问您一些与您抚养_____经验有关的问题。我也会问您与您的家庭对孩子病因的了解，您申请行政文件、医疗资源、教育服务的经验，您对您孩子所接受到的医疗护理的看法以及您对美国医疗体系内应该做何改变的意见。

Your participation is completely voluntary. You may refuse to answer any questions and can stop the interview at any point. All of the identifiable information will be kept confidential and will be destroyed after my thesis is written. Your decision to participate will not impact the care and resources that your family is receiving from Jefferson Hospital. I would like to audio record the interview so that I would be able to capture all of the pertinent information. Your name, your family's name and any other identifiable information will be assigned a pseudonym. If you'd like me to clarify any questions/anything at any point, feel free to stop me.

我了解这个主题有多敏感，也不想让您感到压力或被利用。您的参与完全是自愿的，所以在这个访问过程当中，您可以随时拒绝回答任何问题，您也可以随时停止我们的采访。要是我说错了什么话，请您直接跟我说。所有可识别的信息都将被保密，不会有任何其他人能听见或看见我们今天访谈的内容。这些资料都将在我写完我的论文后销毁。我对采访进行录音，以确保我没有遗漏任何重要信息。您与家人的名字，或其它任何可识别的信息都将以化名的方式呈现。如果需要我在任何时候对任何问题进行解释，请随时打断我。

Let's begin:

- 1) Can you tell me a bit about yourself and your family? i.e.
 - a. 您能告诉我一些您与您家人的事情吗?
 - b. Where did you immigrate from? How did you come to live where you are now?
 - i. 您是从哪里移民来到美国的? 能告诉我您是如何决定定居在费城的吗?
 - c. Who in your family in the country, and who lives out of the country?
 - i. 您在美国有其他家人吗? 国内还有其他家人吗?
 - d. Who are your support systems here? (family, friends, support groups/church?)
 - i. 在这里, 谁是您的支持系统?
 - ii. Who do you live with? Do they speak English fluently?
 1. 您与谁住? 他们也会说英文吗?
 - e. Tell me about the dynamic within your family – so specifically with your parents and siblings – but also the dynamic within you and your little ones.
 - i. 您能告诉我您家里的互动状态吗? 您有几个孩子? 他们几岁了?
 - ii. Who was diagnosed and with a disability?
 - iii. 谁被诊断出有医疗的需要
- 2) Can you tell me about _____ (the child's name)?
 - a. 能不能请您 (Dennis) (小的) 告诉我他的个性、日常生活和兴趣
 - b. their capabilities, what they need help with in their day to day tasks
 - i. 根据他们的诊断, 他们在日常生活中, 有什么困难
- 3) Who is/are the people that _____ are the closest with?
 - a. 他跟谁比较亲近
- 4) Can you tell me about _____'s childhood, and you and your family navigated the _____'s needs?
 - a. 能不能请您告诉我孩子的成长过程,
 - i. 您怎么提供帮助来符合孩子的需要
 - b. 为了符合孩子的需要您的生活是否需要做调整
- 5) Does _____ need round of clock care/who takes care of _____ if they cannot be fully independent on their own?
 - a. 孩子能不能自理自己的生活?
 - i. 要是孩子不能自理的话, 谁负责照顾她
- 6) How was _____ conditions first discovered? (with your family)
 - a. 这个孩子的情况什么时候发现的,
 - b. Was it in-vivo, or was it post-birth?
 - i. 出生前还是出生后发现的
 - c. Were there any signs shown that may be different from what you know as normal development
 - i. 孩子是否曾经表现出他有特殊需要的迹象
- 7) How did you feel, what were your reactions when you were first told by a medical professional about _____'s condition? Can you describe your feelings when your child was medically diagnosed?
 - a. 当您得知孩子的特殊需要的时候, 您的反应是什么
 - b. How did the diagnosis impact you and your family?
 - i. 孩子的诊断如何影响了您和您的家庭

- c. 您在孩子的医疗诊断之前，对自闭症有什么了解？
- 8) Who did your family reach out for _____ care?
- 您是否曾经向谁提出过协助的需求
 - 向谁协助的需求
- 9) Were your family members ready to take care of an infant
- 您与您的家人们是否准备好照顾这个孩子
- 10) Who were the professionals that they would see routinely as a child?
- 孩子多常与医疗专业人员见面
 - 那些医疗专业人员 – 语言治疗师，复健师于心理治疗师
 - How was it for both _____ and your family throughout the sessions that you had with these professionals
 - 能不能请您告诉我您与孩子和医疗专业人员的互动情况
- 11) Can you explain to me how the information about the diagnosis was explained to you?
- 您能不能告诉我您的医疗人员如何向您解释孩子的医疗诊断
 - Are there aspects of the doctor's interpretation that you agree and disagree with?
 - 您对医疗人员的解释有没有任何同意或不同意的地方
 - 医疗人员们有没有提供您任何资源，他们是否有提供孩子后续情况的信息。
- 12) *Can you explain to me your experience after the diagnosis with the medical system?*
- 您能不能解释孩子诊断后您和您孩子与医疗系统的的互动情况。
- 13) What professional/communal resources do you and your family utilize regularly? Did these resources meet your expectations?
- 您与您的家人们经常用那些专业/公共资源？这些资源符合您的要求吗？
- 14) 您用过别种治疗方法吗？用过不一样的医疗系统吗？
- 15) What goals and expectations did you have for your child ?
- 您对您孩子的期望是什么？
- 16) Can you describe your experience raising _____ (child's name).
- 您能说说抚养_____孩子的经验吗？
- 17) What do you think caused your child to have this disability?
- 您觉得您孩子的情况是什么造成的？
 - What did you know about the condition before your child was diagnosed?
 - 能不能请您解释一下在您孩子的医疗诊断前，您对她的情况有什么了解？
 - Do you think its genetics? Environmental factors? Spiritual or religious factor?
 - 您觉得是基因，环境污染，还是宗教因素？
 - 您觉得在你们社区或文化里的人们怎么了解您孩子的医疗诊断和特殊情况？
 - Has your thought on the cause of your child's disability changed?
 - 您对造成您孩子的情况的原因的看法有什么改变吗？
- 18) Can you tell me about what it was like when you shared the diagnosis with other family members?
- 您能跟我解释当您与您其他家庭成员们共享诊断结果时是怎么样的吗
 - Who did you decide to tell, and who, if so, did you decide not to tell?
 - 您决定跟谁说了_____的情况，决定不跟谁说
 - 为什么？
 - How did they react to the diagnosis?

1. 他们的反应是怎么样的
- c. To what extent does your extended family understand your child's condition?
 - i. 您觉得您的家人朋友们能了解您孩子的情况和特殊需要到什么程度吗?
- 19) Can you tell me how you were connected to resources needed for _____'s care, and for your support?
 - a. 您能解释一下您是怎么找到你孩子需要的资源, 和您需要的支持的吗?
- 20) Can you tell me about the resources that you decide to seek out to, and why?
 - a. 您能跟我说一下您决定寻找以及使用哪些资源吗? 为什么?
 - b. What was your experience seeking out to them?
 - i. 您寻找这些资源的经验是怎么样的?
 - ii. Were the resources in your native language, if it was not English? Did
 - iii. 那些资源是您能懂的材料吗? 如果是的话, 您有没有用哪些资料?
 - iv. they have material for your families who may not be fluent in English?
 1. 您是否收到给您英文说得不好的的家人们读的材料?
 - v. Was there guidance throughout the process of seeking out resources?
 1. 您找资源的过程中有没有任何指导?
- 21) Were there potential barriers/help that along the way? 您能不能跟我说一下在您抚养孩子成长需用资源的过程中, 您有没有遇上什么困难?
 - a. How do you think your child has improved?
 - i. 您觉得这些资料和治疗对您孩子的成长有帮助吗?
- 22) Can you tell me about your experience receiving medical care for your child's condition?
 - a. 您能跟我说一下您与您孩子收到医疗服务的过程的经验吗?
 - b. Do you agree with the medical professional?
 - i. 您有什么赞同的, 有什么得批评的?
 - ii. 您是否同意医疗人员的意见?
 - c. Would you prefer the doctors to approach the interactions with you and your child differently?
 - i. 您是否希望医生以不同的方式处理与您和您的孩子的互动?
 - ii. 是的话, 您能结识一些能改变的方式吗?
- 23) (if the child has siblings)
 - a. How does your child's diagnosis affect their siblings lives in any way? In the community?
 - i. 要是有特殊情况的孩子有兄弟姐妹的话, 他们有没有对孩。。。
- 24) Can you share with me some of your fears/anticipations for your child as they are growing older?
 - a. 您能和我分享一下您对您孩子长大后的恐惧和期待吗?
- 25) Is there anything that you hope/wish that your family/friends and other individuals should know about your child/child's condition?
 - a. 有没有哪些关于您孩子的情况, 您希望您的家人们, 朋友们, 社会中其他人能理解?
- 26) Can you share with me what you think has been the hardest part of raising your child? What is the most rewarding part?
 - a. 您能与我分享一下抚养您孩子最困难的部分是什么, 最值得的部分是什么?

- b. Are there specifically challenges that you faced that you wish could have been different?
 - c. 有什么曾经面对过的特定困难希望有所改变，或有所不同？
- 27) What do you think should change/emphasized or maintained so that your experience and other first-generation Asian American parents like you will have an easier time **navigating** their child's diagnosis?
- 28) 您认为在我们社会、法律或医疗系统里应该改变、注重或保持什么好让其他有特殊情况的第一代亚裔家长们能更轻松地面对他们孩子的诊断和治疗？
- a. How do you think this can be done?
 - i. 您有没什么想法能做到这些改变呢？
 - ii. 觉得这事能怎么达到呢？
- 29) Is there anything else that you think would be important for me to know that I did not ask?
- a. 还有什么您认为对您来说很重要的事情我没有问到？

Ending question

- 30) Can I contact you through email or phone if any questions arise as I'm reviewing our conversation/writing my paper?
- a. 我要是有问题的话，能与你保持联系吗？

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