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Navigating Service Experiences for Children with ASD: A Critical Analysis of Immigrant Parent's Perspective through Bourdieu's Capital Lens

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Education

by

Hui Zhang

Committee in charge:
Professor Diana J Arya, Chair
Professor Rachel Lambert
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June 2024

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May 2024

Navigating Service Experiences for Children with ASD: A Critical Analysis of Immigrant
Parent's Perspective through Bourdieu's Capital Lens

by

Hui Zhang

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Education

• University of California Santa Barbara Ph.D., Special Education	Sept 2019-June 2024
• University of California Santa Barbara M. A., Special Education	Sept 2017-Feb 2021
• University of Missouri Kansas City LLM, Master of Law, Corporate law	Aug 2008-Dec 2009
• Wuhan University, China Master of Law, Corporate Law	Sept 2003-June 2006
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Publications

Zhang, H., and Chen C. (2024). A Systematic Review of Factors Related to Immigrant Parents' Choices Toward the Services for Their Children with Autism Spectrum Disorder. *Review Journal of Autism and Developmental Disorders*.

https://doi.org/10.1007/s40489-024-00431-8

Zhang, H., and Arya, D.J. (2024). The Importance of 'Guanxi' for Parents of Children with Autism: A Study of Social Capital in Navigating School Sources.' *Disability and China (Special Issue on Review of Disability Studies)*. Volume 18, Issue 4. https://rdsjournal.org/index.php/journal/article/view/1286/2696

Zhang, H., and Arya, D.J. (2023). Tracing Ideological Tensions in Adopted Legislation for Inclusive Education in China. *Linguistics and Education.* Volume 78, https://doi.org/10.1016/j.linged.2023.101245.

Zhang, H. (2023). The Mental Stress of Immigrant Parents of Children with ASD in the United States During the COVID-19 Pandemics: A Study from Ecological System Perspective. *International Journal of Special Education*, *38*(2), 1–13. https://doi.org/10.52291/ijse.2023.38.17

Zhang, H., Qian, X., & Singer, G. H. (2022). Experiences of Chinese Parents of Children with Autism Spectrum Disorder Advocating for Inclusive Education. *International Journal of Special Education (IJSE)*, 37(1).

https://doi.org/10.52291/ijse.2022.37.27

Zhang, H., and Chen, C. (2021). They Just Want Us to Exist as a Trash Can: Parents of Children with Autism Spectrum Disorder and Their Perspectives to School-Based

Bullying Victimization. *Contemporary School Psychology*. https://doi.org/10.1007/s40688-021-00392-3

Singer, G.H.S., Early, J., Buschor, T., Hoerberg, D., & **Zhang, H.** (2021): Writing as physical and emotional healing: an umbrella review of meta-analyses. *The Routledge Handbook of International Research on Writing: Human Development, Culture, and Digital Spaces. New York & London. Routledge/Taylor &Francis*. https://doi.org/10.4324/9780429437991-32

Manuscripts Under Review and In Preparation

Zhang, H. 'The Role of Virtual Reality Technology Plays in Special Education- A Case Study at Harding Elementary School.'

Zhang, H. 'Parents-School Partnership: Accommodation and Adaptation of Immigrant Parents of Children with ASD in School-Based Reading Activities.'

Zhang, H., 'Critical Reflection on Cultural Barriers of Special Education Research about Attitudes of Chinese Teachers: A Systematic Review.'

Research Experience

2024-Now	Chinese Autism Resources and Empowerment Service（CARES, NFO） Director of Autism Research and Policy. I oversee and direct research initiatives focused on autism and/or other neurodevelopmental disorders, particularly in the context of the Chinese-speaking population.
2022-2024	Graduate Student Researcher, Community-based Literacy Practice in the MTSS (multiple-tiered supporting system): Virtual Reality Program in Cooperation with Harding Elementary School (Santa Barbara, CA; NSF-funded project). Principal Investigator: Dr. Diana Arya I participated in grant writing, coordinated with and supervised undergraduate students' classroom practice, assisted with field observations at the school and data collection, and conducted literature reviews to inform the research design.
2021- 2024	Dissertation: A Critical Analysis of Experiences of Immigrant Parents of Children with ASD on What Makes a Good Service from a Sociological Lens. IRB was approved in November 2021—A mixed-method study. Principal Investigator: Dr. Diana Arya Two manuscripts were published (the first author) Two manuscripts under preparation (the first author)

2020-2021	Graduate Research Assistant, Telehealth Counseling Intervention for Parents of Infants Treated in the Cottage Hospital NICU; Meta-analysis, Interpretative analysis. Principal Investigator: Dr. George Singer One book chapter was published (the fifth author)
2019-2023	Independent Research, Parents of children with autism in China and their advocacy experiences in China. IRB was approved in September 2020 Principal Investigator: Dr. George Singer Four manuscripts were published (the first author)
2020- 2023	Independent Research, Inclusive education in China, taking an elementary school based in Chaoyang district, Beijing, as a field study example. IRB was approved in May 2020. Interpretative analysis Principal Investigator: Dr. Diana Arya One manuscript under preparation (the first author)
2022-2024	Funded project cooperated with Xinhua Compassion and Education Foundation, Experiences of School Psychologists in the Remote Areas in China. Quantitative and Qualitative study. Principal Investigator: Chun Chen (The Chinese University of Hong Kong (Shenzhen)) One manuscript under preparation (the first author)

Conference Presentations

2024	**Zhang, H,** Chun Chen (2024, April). 'Factors Influencing Culturally Diverse Parents' Service Decisions for Children with Autism' The Annual Meeting of the American Education Research Association (AERA) 2024, Philadelphia, in-Person.
2023	**Zhang, H,** Diana Arya (2023, April). 'Tracing Ideological Tensions in Legislation for Inclusive Education in China.' The Annual Meeting of the American Education Research Association (AERA) 2023, Chicago, in-Person.
2023	**Zhang, H** (2023, March). 'Immigrant Parents of Children with Autism during the Pandemics.' CEC 2023 Convention and Expo, Louisville, in-Person.
2022	**Zhang, H** (2022, April). Social Capital and Parental Advocacy Experience in China. The paper section at the Annual Meeting of the American Education Research Association (AERA), San Diego, in person.
2020	**Zhang, H** (2020, May). The Disconnect Reality between Adopted Legislation and Parental Experiences in Advocacy. Santa Barbara, The GGSE Research Symposium, online.

Journal Reviewer Experiences (Part)

2024 Section Editor of DIKSI UNY Journal — The Official UNY Scientific Journal

2024 Reviewer for the International Journal of Developmental Disabilities, the International Journal of Special Education, etc.

2023 Reviewer for 2024 AERA Meeting for SIG ‘Special and Inclusive Education Research.’

2022 Reviewer for 2023 AERA Meeting for SIG ‘Special and Inclusive Education Research.’

2022 Reviewer for the International Journal of Special Education

Teaching Experiences

2024 Teaching Assistant, University of California Santa Barbara, CA.
Class: Introduction to Child and Adolescent Development (Course code: ED111), in-person, teacher education program (TEP) class, graduate-level course. I lead discussion sessions and supervise classroom education practice. This course is connected with a teacher credential program provided by UCSB.

2023 Teaching Assistant, University of California Santa Barbara, CA.

Class: Community-Based Coastal Literacies (Course code: ED139), in-person, under-graduate level course. I lead discussions on disability models in context and supervise classroom literacy education practice. This course is connected with a university-school partnership with Harding Elementary, Santa Barbara, CA.

2023 Online course lecturer on autism for the public, *YGX Music Therapy* Co., Ltd

I designed a course titled *Understanding Autism: Strategies for Families and Caregivers*. This comprehensive course addressed autism spectrum disorder, communication strategies, and behavior management, targeting special education practitioners, parents, and caregivers. Leveraging video lectures, live webinars, and interactive elements like case studies and role-playing, I ensured effective program design, delivery, and evaluation while promoting inclusive learning environments and adaptive technologies.

2021-2023 Teaching Assistant, University of California Santa Barbara, CA.

Class: *Research Methodology in Communication* (Course code: COMM 88), In-person and online; Quantitative methods (factorial design, survey, experimental design, single-subject design, content analysis, etc.) and qualitative methods (interview, grounded theory, etc.); Undergraduate level course. 20 hours/week, 60 students each quarter.

I mentored and provided individual support for students on course-related topics and research projects for the course of communication methodology online and in-person models. It was developed and led interactive tutorials and workshops on research methods, statistical analysis and data interpretation.

2012-2017 Lecturer at Xiamen University, International College, China.

I designed and delivered undergraduate students' lectures on corporate law (English and Chinese), corporate governance, and business ethics. Also, I developed and evaluated course materials, including syllabi, assignments, exams, and case studies and mentored and advised students on their academic and career goals in corporate law. I contributed to the department's research by presenting papers at conferences and workshops and publishing articles in peer-reviewed journals.

Other Professional Experience

2009-2012 Senior Attorney, *Greatway Advisory Corporation* based in Shanghai.

Provided strategic legal advice and support to senior management and business units on various corporate legal issues, including contracts, compliance, intellectual property, and litigation. Drafted, reviewed, and negotiated complex legal agreements, including contracts, licenses, and service agreements. Managed and resolved legal disputes and negotiations with clients, partners, and regulatory authorities. Conducted legal research and analysis to stay abreast of changes in laws and regulations affecting the corporation.

2006-2008 Junior Attorney, *Gide Loyrette Nouel*, Shanghai office

Drafted, reviewed, and negotiated complex legal agreements, including contracts, licenses, and service agreements. Collaborated with cross-functional teams, including HR, finance, and operations, to provide legal guidance on key business initiatives.

Volunteer Activities

2023 Guest speaker for autism awareness month event sponsored by Chinese American Autism Association (Online, April 1st, 2023)

2022 Guest speaker for autism public awareness event hosted by YGX Music Therapy Co., Ltd (Online, March 30, 2022)

2021 Volunteer teaching assistant at a winter camp for children with autism and special needs organized by an NGO based in New York(online)

2018 Volunteer teacher in the inclusive classroom at Goleta Valley Junior High

2017-2018 Volunteer in the Peer Advisor program for UCSB students diagnosed with autism, supervised by Counseling, Clinical, and School Psychology of UCSB.

Honors and Awards

2024	The runner-up of the 13th Grad Slam (graduate research presentation contest), Preliminary Round. University of California Santa Barbara
2024	Department of Education Excellence Award for Research, University of California Santa Barbara
2024	Thomas G. Haring Memorial Fellowship, University of California Santa Barbara
2023	Phillip and Helen Green Fellowship, University of California Santa Barbara
2022	GGSE Doctoral Dissertation Fellowship, University of California Santa Barbara
2021	Gale and Richard Morrison Fellowship, University of California Santa Barbara
	GGSE Travel Grant, University of California Santa Barbara
2020	GGSE Fellowship, University of California Santa Barbara
2019	GGSE Fellowship, University of California Santa Barbara

Certificate

From 2023	Advanced Certified Autism Specialist (US)

Languages

Biliterate in Mandarin and English.

ABSTRACT

Navigating Service Experiences for Children with ASD: A Critical Analysis of Immigrant Parent's Perspective through Bourdieu's Capital Lens

by

Hui Zhang

Researchers interested in understanding the perspectives of U.S. minoritized parents of children with special needs often recruit participants based only on their ethnicity (e.g., Zuckerman et al., 2015; Jegatheesan, 2011; Chiang, 2014). However, this strategy masks the additional, unique challenges of minoritized parents who immigrated to the U.S., leading to potential biases in findings. Such a concern is supported by researchers who have observed significant social-political differences between immigrant and native-born parents from ethnically minoritized groups (Berry et al., 2006; Fernandez et al., 2018;). In addition, combining acculturating and domestic minoritized groups based on race may be misleading as critical characteristics, like ethnic subgroup, socioeconomic position, and duration of residence, are often rendered invisible (Song et al., 2012; Bornstein, 2017). Moreover, there has been little research examining immigrant families' experiences using a critical framework related to capital theories to date; such a dearth in research is particularly concerning given that foreign-born immigrants make up 13.6% percent of the total U.S. population (U.S. Census Bureau, 2021).

A two-study critical approach is applied in this research: the first study is a systematic review that adopts a quantitative perspective synthesizing studies that have reported the relationship between variables of immigrant or minority parents and their choices of services; the second study employs qualitative methods to delve into service-related perceptions, offering qualitative insights into immigrant parents' experiences, which is grounded on the notion of social status and power relations (Bourdieu, 1986) in order to explore the subjective experiences of social structures that immigrant parents must navigate when advocating for their children with special needs.

The findings of this research offer new insights into the intricate interplay of cultural, social, and structural factors influencing immigrant parents' engagement with the special education system. These insights extend beyond ASD, informing culturally responsive policies and practices for parents of children with various special needs. The research underscores the necessity of empirical evidence to support culturally responsive policies and practices, urging researchers to incorporate variables identified in the study into parent-school interaction research. Educator training is advocated, alongside the development of culturally sensitive special education services that acknowledge the complexity of cultural issues.

Chapter I Introduction and Literature Review

1.1 Introduction

Parents of children with special needs' negative experiences with services have been extensively documented with little mention of any positive experiences (Stanford et al., 2020). For instance, despite the breadth of resources offered through and outside of school, parents of children with ASD (Autism Spectrum Disorder) frequently complain that their service requirements are unfulfilled (Wei et al., 2014). Consequently, parents with children with ASD show greater rates of anxiety, sadness, and irritation than families of typically developing children (Duarte et al., 2005; Lu et al., 2015). Further, parents of children with special needs represent a linguistically and culturally diverse group, and given the inequities of institutional acknowledgement and support, researchers have highlighted the particular perspectives and experiences of ethnically marginalized parents of children with special needs. And yet, as we look deeper into this minoritized group, we can see another group—immigrant parents of children with special needs.

Within this context, the levels of stress typically experienced by immigrant parents, who are daily navigating the cultural and linguistic complexities of living outside their home country, can be further compounded by the challenges of navigating the special education systems in the US (Shorey et al., 2020).

It came to my attention that when researchers investigated how immigrant parents of children with ASD in the United States interacted with professionals or accessed services, recruitment of participants was uniformly based on ethnic backgrounds.

The use of a race- or ethnic-based recruitment technique can be beneficial in understanding the challenges that parents of diverse cultural backgrounds are experiencing; nevertheless, such an approach may also contain a concealed bias that these difficulties are comparable just because of the common cultural background of the participants. Immigrant families that share ethnic categories with domestic family groups may overlap with one another in terms of perspectives and experiences; however, researchers have also noted differences between immigrant parents and native-born minority parents (Raleigh &Kao, 2010; Fernandez et al., 2018; Bornstein, 2017). According to Bornstein (2007), the specificity in acculturation science studies may be misleading when acculturating groups are combined with domestic minoritized groups just because they are similar in race. Such combining excludes a series of key variables (such as subgroup ethnicity and immigration status) and differences (such as income level, socioeconomic status, and length of stay) across such groups (Song et al., 2012; Bornstein, 2017). As an example, first-generation Latino families and native-born Latino families might differ more in terms of their immigrant history; distinct cultural customs, awareness of social norms in the United States, and even in terms of languages and respective cultural meanings can differ as well. Furthermore, grouping subculture groups based solely on race without considering experiential and cultural differences between them raises the likelihood of inappropriate and erroneous overgeneralizations (Bornstein, 2017). In short, minoritized immigrant and nonimmigrant families confront similar obstacles and difficulties, such as prejudice and discrimination, but they can differ significantly in terms of participant characteristics, such as “age at immigration, time spent in the culture of the destination, and so on” (Bornstein, 2017, p. 24).

For this dissertation study, I aimed to conduct two interrelated explorations to clarify what we know about minoritized immigrant parents of children with special needs, and what insights we can gain from subsequent research focused on this particular population. The first is a systematic review study of existing research on factors influencing parents' choice of services, and the second is an empirical study of 13 immigrant parents who participated in interviews about their experiences as they navigated the special education system in the US. Through both of these explorations, I aimed to clarify the perspectives and experiences of immigrant parents' perspectives on what constitutes a good service based on their own experiences.

To define immigrant families, I used Singh and colleagues' (2008) description of immigrant families, which divided them into three categories: "foreign-born children with both immigrant parents (first generation), US-born children with both immigrant parents (first generation), and US-born children with one immigrant parent (first generation)" (p.758). Parents who were born in the United States are not included in this research since they do not meet the criteria for participation.

The overarching research question for my study is: What are the perspectives and experiences of immigrant parents in the U.S. who have children with ASD when they navigate services for their children? From this main question, I aim to address the following lines of inquiry:

- What goals or expectations did immigrant parents have about their children in terms of special education services in the US?

- What are the features of practitioners/professionals/services that immigrant parents find most appealing?
- What are immigrant parents' main concerns/considerations while deciding on an intervention, service, or agency?
- What changes, if any, are observable in immigrant parents' perceptions of what constitutes intervention service of quality for their children?

Under section 4.3 of Chapter IV Methodology-'Development of Research Questions', I will provide a full description of the procedure of formation of these research questions.

1.2 The Importance of Social-Cultural Perspectives of Disabilities

The perspectives and dispositions of an individual are influenced by cultural elements and personal encounters. In order to evaluate the perspectives of stakeholders regarding services in social contexts, it is essential to examine the dynamics of interaction between individuals with disabilities and socially constructed environments (Darcy & Taylor, 2009). This comprehension is crucial for gaining an understanding of the struggles faced by parents who are advocating for their children who have been diagnosed with ASD, as it illuminates the sociocultural construction of disability. It is important to analyze the complex relationship between disability and its surroundings to attain a thorough comprehension of these subjective experiences.

1.2.1 Disability Models: Different Ways of Understanding Disabilities

The disability model is an important concept in disability study, which is an interdisciplinary study that brings together social sciences, humanities, and special education to holistically understand disability as a cultural, historical, and value-related formation, instead of just a medical category (Barns & Mercer, 2010). More importantly, disability models explain how these understandings about disability have been translated into public policies and practices in different settings, including clinics and classrooms.

Throughout history, different models of disability have played a pivotal role in shaping societal perceptions, attitudes, and policies regarding disability. In this section, I will delve into the historical development of major disability models, emphasizing their similarities and differences.

Historically, disability was predominantly understood within the framework of the medical model (Smith, 2009). Deviations from typical bodily and functional attributes were pathologized and viewed through a lens of abnormality, contributing to the institutionalized practice of subjecting individuals with disabilities, particularly children, to intensive examination and evaluation by medical specialists (Braddock & Parish, 2001; Smith, 2008). This medicalized perspective positioned individuals with disabilities as objects to be diagnosed and treated, often overlooking their unique experiences, needs, and capabilities.

The medical model considers the person with disabilities to be the problem, and it searches for solutions to the individual's problem. Even though it continues to be popular in medical schools and medical research, it has lost popularity among those who are concerned about the general rights of people with disabilities (Harpur, 2012). Despite the critics of the medical paradigm of Autism because of its narrow focus on physical symptoms, the preeminent cultural narrative of ASD underpinning special education and representations more broadly brought up now is still a biomedical one (Bigby et al., 2019). Under the modern medicalized narratives, ASD represents a neurodevelopment mental disorder located in defective brains which is believed to cause impairments in communication (e.g., atypical use of language), social interaction (e.g., avoiding eye contact), physical movement and behavior (e.g., fixation to certain objects).

However, the landscape of disability models has evolved significantly over time, giving rise to alternative perspectives that challenge the traditional medical model and offer alternative perspectives that aim to promote inclusivity, social justice, and empowerment. One such model is the social model of disability, which posits that disability is not solely a result of an individual's disabilities but is profoundly influenced by societal barriers and discrimination (Oliver, 1997). In other words, the social model posits that disability arises not only as a result of underlying physical difficulties but also as a result of the barriers that individuals encounter when attempting to interact with their environment (Drum et al., 2009). A social-model-based approach to disability focuses on the social dysfunction that is inherent in the condition and the ways in which the failure of public services might influence the lives of people with disabilities when interacting with their surroundings (Kapp et al., 2013). This paradigm shift encourages a focus on removing environmental, attitudinal, and systemic barriers to enable individuals with disabilities to fully participate in society (Shakespeare, 2006). The social model aligns with the principles of equality and inclusivity, emphasizing the need to address discrimination and create an accessible and inclusive world for all.

Building upon the social model, the biopsychosocial model takes a holistic approach to understanding disability, recognizing the interplay between biological, psychological, and social factors in shaping an individual's experience of disability (Engel, 1977). This model acknowledges that disability is not solely a medical issue but is also influenced by psychological well-being and social determinants, further emphasizing the importance of addressing all aspects of an individual's life.

While these models have made significant strides in challenging the medicalization of disability and promoting inclusivity, they are not without their criticisms and limitations. Critics argue that the social model, for example, may downplay the importance of addressing the actual impairments individuals may face, potentially neglecting their medical needs (Shakespeare, 2006). Similarly, the biopsychosocial model, while holistic, may still place an undue burden on individuals to adapt to a society that remains inadequately accommodating.

One disability model has gained prominence in recent years, which is the neurodiversity model. The model recognizes neurological variations, such as autism, ADHD, and dyslexia, not as pathologies but as natural variations of human neurology (Silberman, 2015). In the neurodiversity paradigm, these conditions are considered a part of the rich tapestry of human diversity rather than deviations from an arbitrary "norm."

The neurodiversity model emphasizes that society should not focus on "fixing" or pathologizing individuals with neurodiverse conditions but rather on accommodating and embracing these differences. Advocates of neurodiversity argue that the value of neurodiverse individuals lies in their unique perspectives, talents, and contributions to society. By recognizing and celebrating neurodiversity, we can create more inclusive and accommodating environments that allow neurodiverse individuals to thrive.

The emergence of various disability models and paradigms has sparked ongoing discussions and debates within the disability community and among scholars. It is imperative to acknowledge that these models are not mutually exclusive but rather exist along a continuum, providing different perspectives for comprehending disability. Recognizing the diversity among individuals with disabilities, it becomes evident that no single model can fully encapsulate their multifaceted experiences.

For example, the medical model, despite its criticism for pathologizing disability, continues to serve a crucial role in diagnosing and treating medical conditions. Simultaneously, the social model and the biopsychosocial model, while transformative, may not encompass all the complexities of an individual's disability experience. Therefore, these models should be seen as complementary rather than mutually exclusive, each offering valuable insights into disability from different angles.

In addition to the disability paradigms discussed above, it is essential to also recognize that there are other types of disability paradigms, each offering unique perspectives on disability. These paradigms do not exist in isolation; they often overlap in both content and time and can coexist within the same individual or context, reflecting the multifaceted nature of disability.

The graph about disability models below created by Shir Grunebaum provides an overview of disability models which is publicly accessible online.

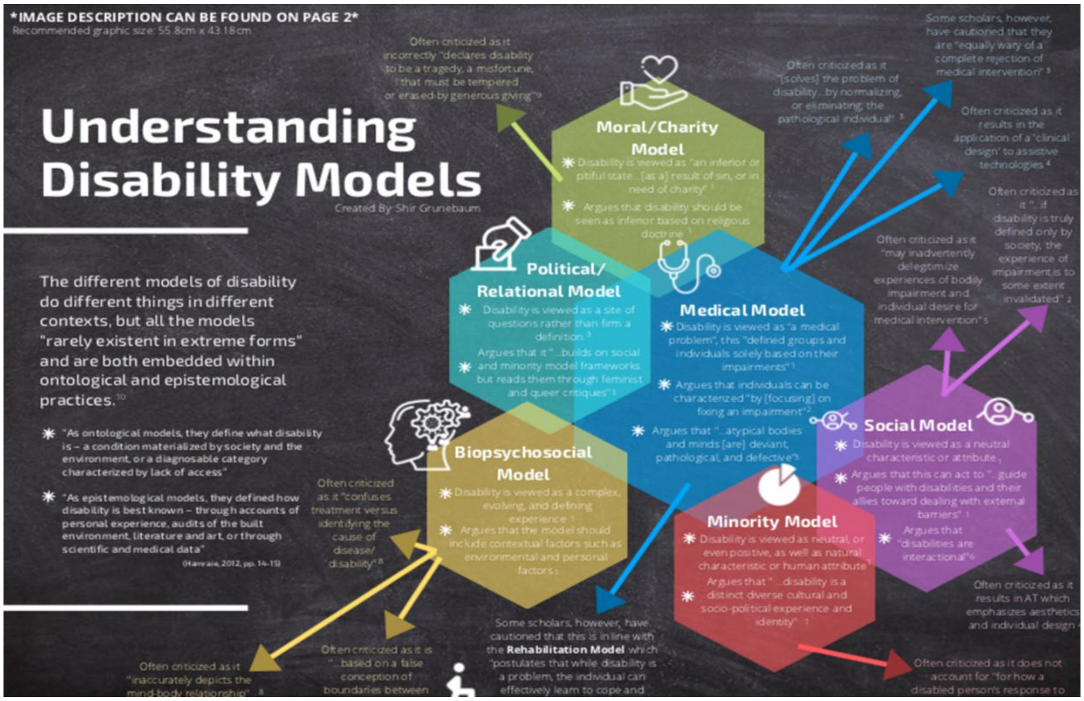


IMAGE DESCRIPTION CAN BE FOUND ON PAGE 2

Recommended graphic size: 55.8cm x 43.18cm

Understanding Disability Models

Created By: Shir Grunebaum

The different models of disability do different things in different contexts, but all the models "rarely existent in extreme forms" and are both embedded within ontological and epistemological practices.[10]

- "As ontological models, they define what disability is – a condition materialized by society and the environment, or a diagnosable category characterized by lack of access"
- "As epistemological models, they defined how disability is best known – through accounts of personal experience, audits of the built environment, literature and art, or through scientific and medical data"

(Hamraie, 2012, pp. 14-15)

Moral/Charity Model

- Disability is viewed as "an inferior or pitiful state…[as a] result of sin, or in need of charity"[1]
- Argues that disability should be seen as inferior based on religious doctrine[1]

Often criticized as it incorrectly "declares disability to be a tragedy, a misfortune, that must be tempered or erased by generous giving"[9]

Political/ Relational Model

- Disability is viewed as a site of questions rather than firm a definition[3]
- Argues that it "…builds on social and minority model frameworks but reads them through feminist and queer critiques"[3]

Medical Model

- Disability is viewed as "a medical problem", this "defined groups and individuals solely based on their impairments"[1]
- Argues that individuals can be characterized "by [focusing] on fixing an impairment"[2]
- Argues that "…atypical bodies and minds [are] deviant, pathological, and defective"[3]

Often criticized as it "[solves] the problem of disability…by normalizing, or eliminating, the pathological individual"[3]

Some scholars, however, have cautioned that they are "equally wary of a complete rejection of medical intervention"[3]

Often criticized as it results in the application of a "clinical design" to assistive technologies[4]

Some scholars, however, have cautioned that this is in line with the **Rehabilitation Model** which "postulates that while disability is a problem, the individual can effectively learn to cope and

Biopsychosocial Model

- Disability is viewed as a complex, evolving, and defining experience[1]
- Argues that the model should include contextual factors such as environmental and personal factors[1]

Often criticized as it "confuses treatment versus identifying the cause of disease/ disability"[8]

Often criticized as it is "…based on a false conception of boundaries between

Often criticized as it "inaccurately depicts the mind-body relationship"[8]

Social Model

- Disability is viewed as a neutral characteristic or attribute[1]
- Argues that this can act to "…guide people with disabilities and their allies toward dealing with external barriers"[1]
- Argues that "disabilities are interactional"[6]

Often criticized as it "may inadvertently delegitimize experiences of bodily impairment and individual desire for medical intervention"[5]

Often criticized as it "…if disability is truly defined only by society, the experience of impairment is to some extent invalidated"[2]

Often criticized as it results in AT which emphasizes aesthetics and individual design[4]

Minority Model

- Disability is viewed as neutral, or even positive, as well as natural characteristic or human attribute[1]
- Argues that "…disability is a distinct diverse cultural and socio-political experience and identity"[1]

Often criticized as it does not account for "for how a disabled person's response to

In conclusion, the historical evolution of disability models has seen a shift from the medicalization of disability to more inclusive and socially aware perspectives. The emergence of the neurodiversity model alongside the social and biopsychosocial models illustrates the diverse ways in which we can understand and address disability. Despite their differences, these models share a common goal of advancing the rights and inclusion of individuals with disabilities, ensuring that they are no longer relegated to the position of "other" in society's assessment of their achievements and contributions. None of these models exists in isolation; they coexist and offer valuable insights into different aspects of disability experience. As our understanding of disability continues to evolve, it is imperative to consider the individual's unique experiences and needs while striving for a more inclusive and equitable world.

1.2.2 Studies of Disability Model in Context of Practice and Services

Disability models play a crucial role in providing conceptual frameworks that facilitate comprehension of the multifaceted nature of disabilities. These models offer a range of viewpoints that not only question but also transform our preconceived notions regarding the experience of individuals living with disabilities. Nevertheless, it is imperative to acknowledge that these understandings transcend mere theoretical conceptions. Practical applications are identified in various domains, including policy creation, service provision, and the relationships between individuals with disabilities and societal institutions. The disability models serve a dual purpose of enhancing our comprehension of impairment and exerting significant influence on the lived experiences and possibilities of those with disabilities. The shift from theoretical concepts to practical application highlights the significant influence that these models exert on the well-being of individuals with disabilities and the broader societal context.

For example, critical disability researchers are calling for a more compassionate, rights-oriented service paradigm in the wake of the social model of disabilities, which is different from a medicalized understanding of disability and functionalist solutions that seek to correct embodied inequalities in learning and conduct, and they advocate for a range of treatments and services to ensure that people with disabilities can exercise their human rights (e.g., Bigby et al., 2019).

The mission statement of the United Nations Convention on the Rights of Individuals with Disabilities ("CRPD") contends that the purpose of the rights-based service paradigm is to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, as well as to promote respect for their inherent dignity. The CRPD provides guidance on what actions are necessary to enable persons with disabilities to enjoy their rights in a variety of situations (Harpur, 2012). The rights guaranteed by the Convention on the Rights of the Child include the right to access buildings, schools, programs, and public transportation, the right to live independently and to be included in the community, the right to personal mobility, the right to freedom of expression and opinion, the right to information, the right to have one's privacy protected, and the right to life and the prohibition against torture, as well as the prohibition against cruel, inhuman, or degrading treatment or punishment, are well-established rights (Harpur, 2012).

Studies on providing special education services suggested the importance of incorporating social and cultural factors into consideration when providing services to people with disabilities. For example, Leicester and Lovell (1997) argue that to understand the creation of disability within a certain context, it is necessary to comprehend the social limits that are imposed within a society (Ware& Schalke, 2019). According to researchers who adopted the social model perspective in examining policies or services in practice, society is obviously responsible for the understanding and cause of disability, rather than the individual who has a disability. However, despite the widespread acceptance the social model has gained, some researchers have contended that the social model fails to take into consideration a variety of cultural settings, instead, it articulates and was rooted on primarily the demands of western/white-focused cultures (e.g., Grech, 2009). Moreover, the argument around social models of disability brought the necessity of applying the understanding of disability in diverse world contexts, highlighting the importance of understanding the construction of disability as being specific to sociocultural, religious, and political contexts, respectively.

Sotnik and Jezewski (2005) are widely recognized for their significant and perceptive contributions to the field of disability studies. They provide helpful strategies for addressing the disparities that exist between various cultural viewpoints in the realm of disability services. The research highlights the need to recognize the social and cultural context in the provision of disability services, as individuals with disabilities and their families originate from diverse cultural backgrounds. The acknowledgment of this socio-cultural context is as significant to the actual provision of disability services. They also suggested that there is a blindness to social-cultural factors contributing to the construction of disability, which can be harmful for students in special education. In their work in 2004, they provided an example of how the causal context of disability is typically related to a sickness or genetic issue in Euro-American countries. Findings by researchers from different cultural backgrounds supported this argument, for example, a study on parental advocacy for children with dyslexia in Hong Kong suggested that, despite the fact that there is limited literature on the relationship between the disability paradigm and Confucianism, the premises of Confucianism may have some negative impact on disability education in Hong Kong society (Poon-McBrayer & McBrayer, 2014). Therefore, sociocultural competency, in this sense, involves knowledge and awareness of how economic conditions, race, culture, ethnicity, social context, and the environment influence and shape health, disability, and the delivery of services.

As discussed, while the social model of disability focuses on the societal barriers and discrimination that individuals with disabilities face, the neurodiversity paradigm takes a different approach, emphasizing the acceptance and celebration of neurological diversity. This paradigm has garnered growing attention and significance within the domains of practice, services, and policies pertaining to disabilities. The neurodiversity paradigm has facilitated the emergence of novel techniques in the domains of education and employment. Numerous research studies have been conducted to examine the efficacy of inclusive classrooms that actively incorporate multiple learning styles and provide support for children with neurodiversity. The neurodiversity was originally conceptualized and discussed by activists and researchers of ASD but has expanded to apply to other neurodevelopmental disorders such as attention-deficit/hyperactivity disorder (ADHD) and specific learning disorders (Sonuga-Barke & Thapar, 2021). In the context of classroom practice, the neurodiversity paradigm shifts the focus from viewing students with special needs as having a disability to an examination of the classroom environment as a disabling context where the student's success is limited due to its lack of hospitality, accommodation, or consideration (Den Houting & Pellicano, 2019). For example, a study conducted by Nicolaidis and colleagues (2015) explored the encounters of neurodiverse college students within inclusive educational settings, thereby elucidating the advantages of accommodating diverse cognitive processes and offering personalized assistance.

Moreover, the neurodiversity model has significantly influenced the progression of support programs, ushering in a paradigm shift towards personalized and individual-centered approaches within the realm of services. An insightful publication in 2021 by Sonuga-Barke and Thapar, both esteemed clinical psychology professors based in the UK, underscores the applicability of the neurodiversity model in clinical practice. Their work suggests that interpreting neurodiversity within the context of diagnosis and treatment has proven beneficial for individuals with ASD and ADHD. Additionally, they advocate for a holistic approach that integrates the concept of neurodiversity alongside conventional research and clinical practices. Also, they highlight the compatibility of traditional approaches, such as the medical model, which seeks to provide clinical treatment and additional resources to neurodiverse individuals, with neurodiversity-focused approaches that aim to adapt environments and challenge neurotypical attitudes. These complementary approaches, they argue, collectively enhance the well-being and quality of life for neurodiverse individuals.

In summary, the domain of disability studies has undergone a transformative process, resulting in a vibrant and interdisciplinary sphere. Within this sphere, a multitude of models and paradigms have emerged, facilitating a more profound comprehension of disability and influencing the development of practical applications, services, and policies. The dynamic relationship among the social model, the neurodiversity model, and other conceptual frameworks has facilitated the exploration of novel approaches to foster inclusivity and enhance the agency of individuals with disabilities. As the exploration and integration of these models persist, it is crucial to maintain a steadfast dedication to cultivating a society that is more equitable and inclusive. This entails recognizing and appreciating the distinctive abilities and viewpoints of those with disabilities.

1.3 Cultural Underpinnings of Immigrant Families in the US

1.3.1 Plural Societies

During a discussion of the rise of some social science terms such as *mainstream*, *minority*, and *ethnic group*, Berry (1997), a psychologist known for his work in ecological and cultural influences on behavior, introduced the concept of *plural societies*, stating that these terms stemmed from the reality that immigrant families face an unequal power dynamic when they come to live in a different cultural context. According to Berry, it is a major challenge for immigrants to maintain their original culture while also participating in the host culture, and this disconnect has an impact on how immigrants perceive their ethnic identities and the constructions of personal social identities in their everyday lives. Berry's insights into the challenges faced by immigrant families resonate deeply with the experiences of many individuals and communities navigating the complexities of plural societies. As a member of this community ourselves, my family and I have personally grappled with the delicate balance of preserving our original culture while adapting to the host culture. The process of acculturation, as discussed by Berry, involves not only adopting the practices and norms of the new society but also negotiating our identity in this ever-evolving context.

These personal experiences have highlighted the multifaceted nature of identity formation in plural societies. While we have strived to maintain the richness of our cultural heritage, we have also embraced the opportunities for growth and enrichment that come with engaging in the diverse tapestry of the host culture.

In addition to personal experiences, a wealth of literature in the field of immigration and cultural studies delves into the multifaceted dynamics of plural societies. Scholars such as Portes and Rumbaut (2024), whose research has been widely recognized as a classic in examining the acculturation process and its effects on immigrant communities, have significantly broadened our comprehension of the acculturation process by applying critical psychological and societal perspectives that account for contemporary demographic, economic, and political realities. The significance of social support networks within immigrant communities is underscored, as they serve as a crucial resource in aiding individuals in navigating the intricacies of pluralistic societies.

Moreover, Berry's concept of plural societies underscores the broader societal implications of immigration. It prompts us to reflect on the role of policies, institutions, and communities in facilitating the integration of immigrants into host societies while acknowledging the value of maintaining their cultural identities. The dialogue surrounding these issues remains crucial as societies continue to evolve in an increasingly interconnected world.

Researchers suggested that when individuals move across cultural boundaries, whether as temporary visitors in a foreign culture or as host nationals encountering foreign immigrants, they often undergo a heightened awareness of the culture's presence and its significant influence (Chiu & Hong, 2005). Regardless of their valence, these encounters underscore the prominence of culture in shaping individuals' identities, and these experiences prompt individuals to engage in thoughtful introspection, considering the profound impact of their cultural encounters on their personal development (Spears, 2011). For example, in a study focusing on the role of acculturation attitudes and behaviors among 530 Turkish immigrants living in the Netherlands, immigrants' attitudes in the private-life domain, such as those toward raising their children, involve their heritage and host cultures, which underpin the social construction of identity, as well as their beliefs toward such social constructions (Kizgin et al., 2018).

Therefore, in accordance with this theory of plural society, while analyzing immigrant parents' views about disabilities and services, it is necessary to evaluate both their perceptions of disability and their thoughts about what it means to be a parent of children with disabilities in the United States. Beth Harry, a renowned scholar whose work addresses the intersections of culture, family, and disability, brought up and adopted a cultural reciprocal stance in her works in the field of special education (Harry et al., 1999; Kalyanpur & Harry, 1999). Harry's concept of cultural reciprocal perspectives embodies an approach that encourages open engagement in reciprocal learning opportunities, characterized by respectful dialogue and information sharing. In practice, this approach can be realized through a four-step process:

1. Self-reflection involves individuals becoming aware of the influences of their personal biases, assumptions, and disciplinary backgrounds.
2. Active listening, inviting, respecting, and acknowledging differences in others' theoretical and cultural assumptions, beliefs, definitions, and interpretations.
3. Validation and engagement in reciprocal conversations aim to explain and understand each other's theoretical and cultural assumptions and beliefs, thereby eliminating potential misconceptions or misunderstandings.
4. Collaboration and compromise are essential for reaching a consensus and establishing common ground and shared goals (Slim & Reuter-Yuill, 2021).

This approach emphasizes the importance of self-awareness, active listening, validation, and collaboration in fostering effective dialogue and mutual understanding within diverse cultural and theoretical contexts. Using examples that illustrate the distinctions between Euro-American and non-Western cultures, Kalyanpur and Harry (1999) highlighted the embedded values in the professional practices and legal assumptions that support the practice of special education in the United States. In addition, the authors noted that many of the fundamental assumptions of the Individuals with Disabilities Education Act (IDEA) are unfamiliar and/or difficult for people from non-western cultures or from marginalized groups to trust, given the socio-political and marginalizing experiences in their daily lives.

Therefore, cultural awareness requires the recognition of the values and beliefs that underlie people's actions and awareness, particularly those that have been taken for granted as universal. After a discussion of the plural society and its impact on individuals' cultural experiences, in the next section, I will delve into the perspectives of immigrant parents toward special education practice. In doing so, I will examine how these cultural insights and awareness translate into the unique perspectives and challenges faced by immigrant parents when navigating the landscape of special education to gain valuable insights into the intersection of culture, education, and the experiences of immigrant families.

1.3.2 Factors Affecting Parents’ Choice of Services

According to the findings of studies on parents' interactions with service providers, immigrant parents have had some positive experiences with special education experts and agencies. Parents have identified and reported on a variety of factors that have aided their experiences (Abbott, 2013), such as diagnostic techniques (e.g., Braiden et al., 2010) and communication with specialists (e.g., Rabba et al., 2019). Among all of the factors indicated in this research, efficacy (i.e., creating outcomes), sustainability (outcomes that support long-term goals), structured opportunities to discuss diagnosis and ask questions, and positive interactions (warm, collegial connections with school actors) are among the elements deemed significant to parents in general. For example, a study by experts in the field of parent support since the 2000s, a professor from Macquarie University, Carter and colleagues (2007) informed best practices by practitioners dealing with families of children demonstrating a wide range of health needs. Following interviews with stakeholders (27 parents and 41 health care practitioners), the authors identified the following key practices:

collaborative decision-making, tight working connections, clear communication, and parents' involvement regarding service providers).

Among a handful of researchers who tried to define what constitutes a good service experience from the perspectives of parents of children with ASD is an interview study published by Stanford and colleagues (2020), researchers focusing on developmental assessment from Warwick University in the UK, that discovered three themes that may be important for my research. This team interviewed 17 mothers of children diagnosed with ASD aged between 5 and 10 years old to learn what supports were deemed helpful. By using inductive thematic analysis, a flexible, practical, and widely used qualitative method by researchers to analyze and interpret textual or visual data (Braun & Clarke, 2006), the researchers identified three themes relating to participating mothers' evaluation of a good intervention, which included parent-professional interactions, elements of services (e.g., information sharing, supportive community building, and intervention techniques lecturing), and the way services were delivered (e.g., pull-out vs. inclusive classroom support). While these themes clarify qualities that are important to mothers, none of the participants in this study were from immigrant households in the United States.

While research investigating the perspectives of parents regarding positive service or intervention experiences has contributed to our overall comprehension of what defines a positive encounter, it has yet to explore the unique viewpoints of immigrant parents. The aforementioned studies have not provided any insights into pivotal determinants that impact the decision-making process of parents who are immigrants. Earlier studies attributed variations among parents' choice regarding childcare decisions to their taste and beliefs. For example, Galinsky (1994) claimed that racial-and language-minority parents prefer to use relatives as childcare because they are culturally in favor of relying on family's member who they could trust with in childcare instead of using formal childcare service. However, after conducting a study on parents' choice in childcare decisions, Meyers and Jordan (2006) concluded that, as a consumption decision, parents' choice of services is more associated with and reflects their accommodations to current economic and social realities. These accommodations include parents' education, access to services, and social economic status, rather than their deeply held beliefs and tastes that are ingrained in their cultures. Their conclusions are consistent with an earlier study done by Fuller and his colleagues (2002), they suggested that 'As welfare parents enter the workforce and their incomes rise, so does the likelihood that they will choose a more formal childcare arrangement' (p.10).

According to previous research, the nature of parental decision-making is compounded by cultural, economic, and demographic factors. It is therefore important to examine what is currently being learned from studies of parents of children with ASD and the factors that influence their decision when it comes to choosing intervention and services for children with ASD.

Various factors have been identified as impacting parents' decisions on intervention choices for their young children with ASD based on studies conducted by researchers in the field of ASD and its treatment. There are two types of decision-making variables: explicitly stated decision-making elements and implicit decision-making factors. Explicit factors are those that parents publicly acknowledge and consider, such as professional suggestions or advice from other parents. Implicit factors, on the other hand, include variables that parents may be unaware of, such as specific qualities of the child, parent, or family dynamics (Dardennes et al., 2011; Erba, 2000; Frame & Casey, 2019). Scholars also found other factors might have influenced parents' choices of services. For example, scholars from different universities across US focusing on parents' attitudes toward genetic testing for their children with ASD (Zhao et al., 2021) found that subjective norms, defined as perceptions of what other people (i.e., family members, professionals, and the public) think about whether parents should pursue genetic testing for their children with ASD, as well as their knowledge and self-efficacy about genetic tests, were positively related to their choice of parents on whether to take genetic tests for their children with ASD. As a result of this study, ethnic minority parents were found to have more favorable attitudes toward genetic testing when compared to non-minority parents, which is consistent with previous studies that found that racial/ethnic minority parents were generally more in favor of genetic testing for their children who were suffering from incurable diseases (e.g., Tarini et al.,2009). As a result, it is critical to gain insights into minority parents' intentions to pursue certain services and interventions, as well as the underlying social or psychological factors that influence these intentions, with the goal of providing culturally sensitive and linguistically appropriate services to respect and meet racial/ethnic minority parents' needs.

Moreover, according to studies, parents of children with ASD, regardless of their national origins or cultural roots, are generally reported to have a large involvement in decision-making about their children's interventions (in contrast to parents of children with routine medical requirements) and are often directed by experts such as physicians rather than their own perspectives about their children's needs (Valentine, 2010). Scholars of special education in Australia, Carlon and colleagues (2013) reviewed 16 peer-reviewed studies for the purpose of examining the factors declared by parents of children with ASD as affecting their decision-making on treatment/intervention, and they nominated factors including recommendations from others, the availability of services, accessibility, cost of interventions, the availability and use of other interventions, and research evidence as the factors that play import roles on parents' decision-making. However, a substantial number of implicit variables, including information that clarifies background (e.g., immigrant or non-immigrant, length of stay in the destination culture, and beliefs of ASD) were unaddressed in these studies. Thus, the characteristics discovered by these researchers may be impacted by the content and format of the study questions.

Additionally, parental personal experiences that may be connected to parental decision-making may have been overlooked or were not addressed explicitly in most studies. Future research on the link between explicitly declared and implicit underlying variables, according to Carlon and colleagues (2013), is needed to offer a full picture of the decision-making process of parents. A more recent systematic review, which examined 41 studies reporting implicit factors related to parents' treatment decisions for their children with ASD, highlighted the presence of implicit factors such as challenging behaviors, parental stress, and beliefs about ASD, which seemed associated with the use of specific treatments for children with ASD in particular situations (Wilson et al.,2018). However, because the study's selection criteria and analytic process did not clarify the cultural or linguistic diversity of parents, we are unable to determine if the findings can be applied to immigrant parents as well.

1.4 Parents Advocacy and Empowerment

When educational scholars investigated parents' views and experiences about special education services, they frequently used the term *parent advocacy and empowerment* (e.g., Nachshen, 2005; Trainor, 2010). Although this is not a study about parental empowerment per se, I sought to explore how immigrant parents' perspectives of their roles as advocates differed based on race or ethnic origin and socioeconomic class.

1.4.1 Parental Empowerment and Parental Advocacy

Empowerment and advocacy are concepts frequently employed in research related to the provision of services to families of children with developmental disabilities. These terms are used interchangeably by some researchers, while others draw clear distinctions between them.

For example, as defined by The Family Empowerment Scale (FES) (Koren et al., 1992), **empowerment** can be classified into three distinct tiers: service level empowerment pertains to the manner in which a parent collaborates with agencies that furnish services for their child; community/political empowerment entails **parental advocacy** for enhanced services; and family level empowerment concerns the manner in which a family handles daily affairs within the immediate family sphere.

Parental advocacy is a subset of parental empowerment, according to FES (1992). This classification has also been endorsed by other scholars; nevertheless, the relative importance of advocacy and empowerment may vary. A further suggestion made by Nachshen and Jamieson (2000) is that empowerment and advocacy may not always be intrinsically linked. They suggest that advocacy can manifest in one of two ways: empowered advocacy or unempowered advocacy, wherein empowerment functions as an element within the broader framework of advocacy. Furthermore, according to Nachshen (2005), a Canadian scholar in special education and parents’ support, empowerment is defined as a deliberate, ongoing process through which individuals who do not have an equal share of valuable resources gain increased access to and control over those resources. Nachshen (2015) suggested that empowerment can be classified into three main levels: the community level, organizational level, and psychological level. Additionally, in the form of empowerment, scholars also suggested that empowerment can be understood as both a process involving actions, activities, or structures and an outcome indicating a degree of empowerment attained (Shultz et al., 1995; Zimmerman, 1995). Trainor (2010), a researcher on parents' involvement in special education services, for example, characterizes advocacy as a subset of parental engagement, suggesting the boundary between parent engagement and parental advocacy.

Parental advocacy and empowerment can be difficult to quantify due to the inconsistency of their respective definitions. Effectively examining how participants collectively and individually interpret their experiences in different programs has been the focus of the majority of pertinent research on parent empowerment. Among this research, a few quantitative studies applied different measurements and scales to quantify the impact of parent empowerment and advocacy with varied focus. For example, in contrast to the broader implementation of FES (1992) (e.g., Scheel & Rieckmann, 1998; Dempsey & Dunst, 2004), parent empowerment and efficacy measure (PEEM; Freiberg et al., 2014), and a self-administered questionnaire on parental health-related empowerment devised by Figueroa et al. (2020) has been comparatively less utilized.

However, it is worth noting that most of the research on family empowerment has been predominantly theoretical in nature, with limited emphasis on exploring the experiences of immigrant families with children who have ASD—a gap that this research aims to address. I will investigate how immigrant parents perceive their roles as advocates, considering factors such as race, ethnic origin, and socioeconomic class, while also examining the intricate relationship between empowerment and advocacy within this context. This approach will provide valuable insights into the unique challenges and opportunities faced by immigrant families in navigating the special education system.

1.4.2 Disempowerment of Parents

Parents in the U.S. have long been noted to experience difficulty when communicating with various school actors (school leaders, teachers, special education professionals, etc.) about services for children in need of additional educational support (e.g., Koren et al., 1992; Nachshen, 2005; Porter & Walters, 2017). Such difficulty comes in various forms, including inequitable access to resources, lack of opportunities to share experiential knowledge, and a dearth of invitations for active participation, all of which present as a tangle of issues that warrant careful unpacking (Trainor, 2010). These observed inequities have endured in parallel with national policies like the *Individuals with Disability Education Improvement Act (IDEA,1990), which* is purported to support all students with free education in the most inclusive approach possible (Zirkel, 2015).

Under the provisions of the IDEA, it is mandatory for public schools to provide parents with regular updates regarding the modifications being implemented for their children. Nevertheless, their knowledge regarding services and assistance is frequently lacking (Bower, 2019). Studies examining the reasons why parents choose to homeschool their child with ASD have found that these decisions are often driven by concerns about the challenges faced by students with ASD in traditional public school environments. These challenges include a lack of personalized attention and support, heightened anxiety, sensory difficulties, social isolation, and a higher incidence of bullying among children with autism (Humphrey & Symes, 2010; McDonald & Lopes, 2014).

Nachshen and Jamieson (2000) found from their interviews with 26 parents of children with developmental disabilities that the outcome (i.e., level of expressed empowerment) of parents' advocacy activities depended on the context in which the advocacy actions occurred. Advocacy activities that resulted in positive results (empowerment) for parents occurred when professionals responded favorably and constructively to advocacy, when parents were able to maintain a personal life or sense of space, or when parents were not struggling with their own anxieties and other negative emotions. Parental empowerment is also related to reduced stress levels and an improved quality of life for parents, according to this study. Simply put, the more parents are heard and acknowledged, the more at ease, supported, and, hence, empowered they feel. Disempowerment, on the other hand, is widely defined as the stress, frustration, and pessimism that characterize the lives of caregivers for those with developmental disabilities (Koegel et al., 2003). Given that research on parental empowerment and parental advocacy has remained largely theoretical, and little research has been conducted on the experiences, opinions, and attitudes of parents of children with special needs (Nachshen, 2005), particularly immigrant parents, on a community, organizational, and individual level through the processes or outcomes of parents' empowerment. Examining immigrant parents' attitudes toward what constitutes a good service as a predictor of family well-being variables (Trainor, 2010) is an important investigation to unpack the inequity caused by disempowers.

2.4 Conclusions

According to previous research, the nature of parental perspectives, experiences, and decision-making about services for children with special needs is compounded by cultural, economic, and demographic factors, and based on research (albeit scant), immigrant parents are further compounded within such a context. Researchers and scholars across the fields of parental advocacy, psychology and special education have suggested factors including economic conditions, race, culture, ethnicity, the social context, and the environment as they influence and shape health, disability, and the delivery of services to families of children with special needs. However, the current studies on parents of children with special have not paid enough attention to the unique situation of immigrant parents in the U.S. based on their status as they are adapting and adjusting themselves to the host culture. Such a lack of attention is particularly problematic given the anti-immigrant, nationalistic discourse pervading all institutional outlets. What is even less understood are factors that impact the general well-being of immigrant parents and their ability to advocate for their children with and without sources of empowerment. We also have little understanding of the perspectives of immigrant parents in terms of what constitutes good services for their children. Therefore, in order to gain a better understanding of immigrant parents' perspectives on what constitutes a good service based on their own experiences, I conducted two explorations. First, I dove deep into current related studies of parents' accounts of good educational practices and resources as well as factors that influence parents’ decisions to choose particular school-based interventions and/or services from a sociocultural lens involving their knowledge and awareness of their agency during interaction with their surroundings. Findings from this first study served as a foundation from which I built my second study involving 13 immigrant parents of children with ASD. For both studies, I used a sociocultural framework that centers human experience on societal structures that influence how residents within a given community are viewed and valued.

Specifically, I use the ecological system theory (Bronfenbrenner, 1979,1986)(detailed definitions are seen in Chapter III) as a framework to define social context which is helpful for understanding the different layers of actors involved in an immigrant parent's world of advocating for their child with ASD, and Bourdieu's capital theory (1997) (detailed definitions are seen in Chapter III) helps with understanding the different kinds of value systems in play across these social context layers.

In summary, in order to understand immigrant parents' choices and their experiences with different services and practices in relation to their children with ASD, in addition to Bourdieu's capital theory which focuses on understanding an individual's thoughts and actions as an interplay between societal structures and agents, I also define the structure as a complicated multiple layered environment as established by Bronfenbrenner (1979) and developed by other researchers based on the theory (e.g., Dauber & Epstein, 1993; Garcia & Collet, 1996). I will delve deeper into the definitions of the theoretical frameworks in the next chapter.

Chapter III Theoretical Framework

3.1 Background Introduction

Pierre Bourdieu, a distinguished French sociologist and important intellectual, has significantly influenced multiple disciplines, including education. Bourdieu, who was born in 1930, has made substantial contributions to our comprehension of social structures, power dynamics, and their intersection with education. In addition to being an educator, he was a highly productive author, renowned for his discerning and interdisciplinary approach to social analysis.

Bourdieu's importance in the field of education arises from his capacity to illuminate the covert dynamics and disparities that pervade educational systems. His work questioned traditional beliefs about meritocracy and emphasized the influence of social, cultural, and economic factors on educational achievements. Bourdieu posited that educational institutions frequently reproduce and bolster prevailing social hierarchies, hence impeding underprivileged individuals from attaining equitable chances.

Specifically, Bourdieu has made significant contributions to the field of sociology through the development of a framework that analyzes the relationship between the accumulation of various forms of capital in different social domains and the habitus of individuals, which is influenced by their social backgrounds. In my investigation of the ideological tension embedded in special education legislation in China (Zhang & Arya, 2023) and the social network parents utilize to enroll their children in public schools when the implementation guidelines are ambiguous and unclear, I utilized Bourdieu's capital theories (Zhang & Arya, 2023). Bourdieu's theories illuminate the often-overlooked aspects of educational research by exposing the profoundly ingrained social structures and disparities that impact educational procedures and results. In the absence of this social structure-based lens, researchers may fail to recognize the profound influence of factors such as cultural background, social capital, and habitus on students' experiences and achievements in school.

Moreover, in the context of this study, with the focus on the views of parents' opinions of their children’s service choices, also known as subjective norms (Zhao et al., 2021), align with Bourdieu's notion of habitus, which pertains to the personal experience of objective social structures (Pellandini-Simányi, 2014). The notion of habitus was originally formulated to elucidate the connection between our lived experiences (i.e., practices) and the cognitive processes that arise from them (Bourdieu, 2007). Bourdieu's research highlights that habits and practices are not simply acquired actions but are profoundly ingrained in personal emotions linked to objective social frameworks. This observation is consistent with the idea that regular practice, such as educational decisions and interventions, is shaped by the interaction between personal experiences and external social influences.

In order to define the external social influences, I also use the ecological system theory (Bronfenbrenner, 1979,1986) as a theoretical framework to define social context. This is the best fit for the present study because among a set of other theories that address a broad scope of social contexts theories that contribute to players' behaviors, such as the social cognitive theory (Bandura, 1986), the theory of planned behavior (Ajzen, 1991), theory of practice (Shove, 2003), as well as the actor-network theory (Latour, 1994), the ecological system theory emphasizes the significance of context in comprehending family dynamics and development, as well as the fact that parental behavior does not happen in a vacuum, but rather as a result of immersing in a various range of sources within numerous ecological systems.

3.2 Introduction of Ecological System Theory of Parenting

3.2.1 Background Introduction

The ecological theory, as proposed by Bronfenbrenner (1979/1986), holds that children’ development is greatly impacted by the structural contexts in which parents and children are embedded. Human behavior within the context of nested structures of the environment, as well as the interactions between humans and environmental occurrences, may be better understood by using ecological framework including the following layers:

- Micro-system (the groups that most immediately and directly impact the family, e.g., schools and peers).
- Meso-system (interconnections between the microsystems, for example, between the family and teachers or between the child’s peers and the family).
- Exo-system (links between social settings, for example, parents’ work, media, and neighborhood).
- Macro-system (culture contexts, such as ethnicity, traditions, and social-economic status), and,
- Chronosystem (pattern of life course transitions, such as the shift of disability paradigm from medical model to social model over the past 30 years) (Bronfenbrenner, 1979).

The analysis in this study is limited to micro-systems, meso-systems, exo-systems and macro-systems as a result of constraints related to data sources and quantity. Ecological theory emphasizes the significance of setting in comprehending family processes and growth. Using the ecological system theory as a foundation, researchers proposed that not only does children's development depend on a complex system of relationships within various levels of their environment, but parental knowledge is not acquired in isolation, but rather from a range of sources across many ecological systems (e.g., Blocklin et al., 2011; Tang, 2006). For instance, Tang (2006) discovered a substantial correlation between parental punishment behaviors and possible predictors, including children's early age, male gender, externalizing tendencies, young parents, unemployment, and marital discontent. In their study about the source of parental knowledge in Mexican American families, Blocklin and colleagues (2011) suggested that parental knowledge may involve direct parent-child communication at the most fundamental level of the family microsystem, including children's self-disclosure (children may tell their parents about their experience) and parental solicitation behavior (parents may ask their children about their experience), but it also comes from external sources outside the family, such as their neighbors and school teachers (mesosystem).

In the ecological system theory of parenting, the significance of family influence on different aspects of child development is emphasized. According to the ecological system theory, the child is put at the core of the ecological system (Microsystem), and his or her parents will exert the most immediate influence on the child (Dauber & Epstein, 1993). When it comes to immigrant parents and their cultural orientations, which usually represent their culture underpinning and their class in a society, positioning their families in the macrosystem, their culture and class may help shape how immigrant parents formulate their knowledge regarding their children (Coll et al., 1996).

In conclusion, ecological system theory of parenting provides a way to specify how a child’s development and parents’ behaviors are shaped by multiple-layered environment, which enables researcher to explore whether and how parents’ sources of knowledge and corresponding were formed and linked to their outcomes.

3.2.2 Rationale- How Should Social Context be Framed?

Before analyzing the impact of social environment, I will first define social context. The ecological system theory (Bronfenbrenner, 1979,1986) is the best fit for my study to frame social context. Among a set of theories that address a broad scope of social settings that contribute to players' behaviors, such as the social cognitive theory (Bandura, 1986), the theory of planned behavior (Ajzen, 1991), theory of practice (Shove, 2003), as well as the actor-network theory (Latour, 1994), the ecological system theory (Bronfenbrenner, 1979,1986) is the best fit because it emphasizes the significance of context in comprehending family dynamics and development, as well as the fact that parental behavior does not happen in a vacuum, but rather as a result of immersing in a various range of sources within numerous ecological systems.

The ecological systems theory (Bronfenbrenner, 1979) offers a valuable framework for comprehending how parental behavior is situated within multiple layers of interdependent social circumstances. Parenting decisions are made within the context of the immediate family, but they are also influenced by contexts in which the family is embedded, such as the neighborhood, parents' workplace, local and national policies, and social norms and values associated with the education and upbringing of children.

Ecological systems theory describes social settings of parenting as constant and continuing interactions between parents and circumstances, which serve as the major mechanism for influencing parental behavior throughout time (Swanson et al, 2010). I studied parental behaviors (i.e., parental choice of services, ASD awareness, and contacts with institutions) since these reflect significant proximal processes that have been related with outcomes of choices of services.

Bronfenbrenner's (1979) theory of the family ecological system is a valid framework in which social settings interact with each other and with the individual parent. Bronfenbrenner has put the different factors that affect parenting in order of how close they are to the parents. Here, I've listed them from most close to most distant: microsystem(the groups that most immediately and directly impact the family, e.g., schools and peers), mesosystem(interconnections between the microsystems, for example, between the family and teachers or between the child's peers and the family), exo-system (links between social settings, for example, parents' work, media, and neighborhood), macrosystem(culture contexts, such as ethnicity, traditions, and social-economic status) and chronosystem(pattern of life course transitions, such as the shift of disability paradigm from medical model to social model over the past 30 years)(Bronfenbrenner, 1979).

Using this ecological system theory as a foundation, researchers suggested that the contexts of nested structures are significant socio-cultural contexts that impact parental experiences. For instance, empirical investigations done in accordance with ecological system frameworks discovered and validated relationships between socioeconomic environment, social support, and parent mental health (Wade et al., 2015; Conger et al., 2002). In addition, because children with ASD are more dependent on their parents and surroundings than typically developing children (Belsky, 1984; Wade et al., 2015), parents of children with ASD exhibited significantly greater dependence on circumstances than parents of children with Down syndrome or other intellectual disabilities (Hayes & Watson, 2013).

3.2.3 Application of Ecological System Theory of Parenting in Studies

As discussed before in 3.1, researchers have applied the ecological system theory of parenting in their studies in various disciplines including the investigation on classroom climate, family process and competence, parent knowledge and practices, parental support, peer support, school connectedness and social support of families. The application aligns well with the widely applicable ecological systems theory which highlights the importance of various proximal systems (family members, peers, teachers, neighbors, and educational environment) in the learning and psychological growth of children. Furthermore, by using this ecological system theory as a foundation, researchers suggested that the contexts of nested structures are significant sources of knowledge and psychological stress that impact parental experiences and choices, especially parents of children with special needs. For instance, empirical investigations done in accordance with ecological system frameworks discovered because children with disabilities are more reliant on their parents and surroundings than typically developing children (Belsky, 1984; Wade et al., 2015), mental stress among parents of disabled children is clinically significantly higher than that of typically developing children, and parents of children with ASD experience significantly more stress than parents of children with other disabilities, such as Down Syndrome or other intellectual disabilities (Hayes & Watson, 2013). These studies validated relationships between socioeconomic environment, social support, and parental coping strategies (Wade et al., 2015; Conger et al., 2002).

3.3 Introduction of Bourdieu's Theories

3.3.1 Theory of Habitus

The first theory is the concept of habitus, which was proposed by Bourdieu (1984) as an internalized and embodied social structure that has collectively resulted in perceptions and acts that have a long-lasting nature and have been sustained over time. In an effort to reconcile structure and agency, Bourdieu's approach aims to move beyond the dualism of structure and agency and argues that external structures are internalized into the agent, whilst the agent's activities externalize inter-actor interactions into the field's social connections.

While there are differences in the analysis of interactions between structure and agency between sociologists, such as Georg Simmel, Talcott Parsons, and Bourdieu, they all contributed to the construction of theories in explaining how people's perceptions of what they might become in terms of agency or subjective standards that influence their life choices come into contact with social structure they live in, which is concerned with the subjective experience of objective social structures (Pellandini-Simányi, 2014). For example, Simmel, a pioneer in relational sociology in the 1900s, brought that as society progresses, human knowledge will continue to expand, yet, to sustain the order and stability of a society, Parsons (1972) felt that individuals must satisfy the fundamental criteria of a society, which include attaining goals, adapting to the environment, managing one's own conduct, and integrating new components into the existing environment. Bourdieu (1984) further argued that a power dynamic relation exists in social lives that various levels of society, economics, and cultural capital jointly have formed a class structure where one's own habits, the temperaments formed by long-term social and institutionalized conditioning were influenced by the internalized social structures including bias and traditions. Furthermore, one may become conscious of one's own prejudices as a result of these constant reflections, which are impacted by the desires of individuals in dominating social classes (Bourdieu, 1984).

Researchers also have expanded Bourdieu’s theory of habitus to other dimensions. For example, structural interaction theory, developed by Giddens in 1983, brought together the viewpoints of various sociologists and those in diverse positions, and it went deep into the concerns of human behavior's structural and spatial relationships by using the conceptualization of system, structure, and agency which offers an intriguing way of analyzing society.

Using the notion of habitus, researchers may comprehend the trajectory of a single individual or the trajectory of a group within a social framework that has been deeply embedded in the minds of all actors and has shaped how people perceive events that occur around them (Shortall et al., 2018). Bourdieu’s conceptions of habitus and capital are all interconnected, and he stated that they all change through time, emphasizing the interconnections between them (Grenfell, 2014).

Furthermore, according to researchers, habitus is both a product of and a (re)producer of the social world. For example, Ritzer (1996) emphasized in his study on the modern sociological theory that habitus is a structuring structure, which means it is a structure that structures the social world and a producer/producer of the social world (Ritzer, 1996).

Researchers in the field of science of human nature have suggested that in contrast to habit, habitual practice is an ethical behavior that is underpinned by subjective emotions of objective social structures and that it is not something that can be simply taught and learned as a result of formal education (Aristotle& Urmson,1909; Pellandini-Simanyi, 2014). Taking the example of Binder and Boldero (2012), who conducted a case study in Australia and looked into the existing habitus in planning practice, they concluded that in order to realize a planning practice that leads to productive, livable, and sustainable design, it is necessary to radically challenge the normative assumptions commonly existing in the current planning practice that treating housing planning as a market product, or an investment driven by profit.

3.3.2 Theory of Capital

Overview

Bourdieu's work centers on the role of culture in the reproduction of unequal power relations (Bourdieu & Passeron; 1977). Cultural capital, economic capital, social capital, and symbolic capital are the four fundamental forms of capital in his framework. Among them, economic capital is the most tangible kind of capital since it reflects specific monetary value, income, and assets that can be transferred in the economic realm while symbolic capital is a collection of resources that people may activate when they interact across a network of interrelated domains of interaction. Under symbolic capital theory, each field or domain operates according to its own set of rules, which is independent of the others, and is dynamic in response to changes in agents' locations. Cultural and social capital, on the other hand, are keys for safeguarding the ruling class's uneven access to resources and the perpetuation of privilege. Social institutions are more successful when they are aware of the cultural and social resources accessible to dominant groups.

Social scientists tried to determine and understand how each person fits into the ranking physical and social structure and whether and how people traverse different social subgroups by using the capital theory as a theoretical framework (e.g., Reed-Danahay; 2004; Shen, 2020).

Additionally, subjects' techniques for gaining, activating, and storing cultural, social, and economic capital are very vital to take into consideration. However, because the concept of capital was introduced at a period when critical racial studies had not yet arisen in history, Bourdieu himself did not apply his theories of either capital or habitus to the analysis of racial and ethnic disadvantages. As Horvat and colleagues (2003) stated in their study about social and class differences in the relations between families and schools, the notion of capital only has meaning in the context of the data and the research settings.

Following Bourdieu and other contemporaneous scholars, researchers in the twenty-first century expanded Bourdieu's views by incorporating racialized and ethnicized viewpoints into the discussion. Using Bourdieu's definition of habitus, Reay (2004) developed an understanding of habitus in education studies that recognizes both permeability and continuity over time, while acknowledging both permeability and continuity within a specific context. The classic Bourdieusian study of capital, habitus, and field, according to Richard (2020), is also challenged since it focuses primarily on class disparities, while overlooking the issue of race and racism, as well as the intersectionality of class and race.

As a result, following a critique of postmodern perspectives on culture, agent and structure as well as the intersectionality of class and race, the work of Pierre Bourdieu on capital has been extended and explored to new dimensions, such as community power-dynamic studies (Houston, 2002). For example, Ballet and colleagues (2007) referred to Bourdieu's social capital when analyzing the power dynamics in community-based natural resource management. Addi-Raccah and colleagues (2016), on the other hand, followed Bourdieu's notion of cultural capital and examined teachers' views toward parents in Jewish and Arab schools. As Schubert (2008) suggested, the symbolic domination of agents in the form of capitals may have played a part in all social formations, thus becoming more and more significant in contemporary, advanced capitalist societies. For this study, Bourdieu's conceptualization of social and cultural capital was applied to make sense of the position and experience of immigrant parents of children with ASD with regard to their efforts to advocate for better services and accommodations for their children. Particularly, by examining how these capitals are situated in a wider social context and in relation to other social networks and considering the obstacles immigrant parents have encountered in creating such links, the author applied Bourdieu's capitals theory to explore how immigrant parents' dispositions of what makes a good service are shaped by their past struggles to gain accommodation and services within the field of special education in the United States.

It is common for researchers to use the terms social capital and cultural capital in conjunction to describe the relationship and power dynamics between parental agents and other structures in society (e.g., Trainor, 2010). Due to the limitation of the data as well as the focus of research questions that are not focusing on economic standing (economic capital) or the static comparison of laws or social rules between home countries and host countries (symbolic capital, or field), among the four types of capitals as introduced by Bourdieu (1977/1986), only cultural capital and social capital will be discussed.

Social Capital

Sociologist and philosopher Pierre Bourdieu (1986) characterized such societal privilege as social capital in which individuals activate their social network to gain social advantages or benefits for a variety of reasons, including support for their children. Bourdieu explained that access to such networking tends to be limited to those sharing the same social circle or class, hence privileging institutional familiarity or membership while excluding those who might benefit even more from such enrichment or resources.

Bourdieu (1986/2011) viewed social capital as a form of power that one uses to gain respect and access to tangible resources shared within a particular social group. Building on this premise, researchers suggested that there are three forms of social capital networking: bonding, bridging, and linking (Putnam, 2000; Woolcock,1998). Each form of social capital refers to a method of connection--strengthening ties with others in the same social class (bonding), reaching out to connect with members of other social groups (bridging), and broadening one's base by increasing membership of a social group for a shared goal (linking).

As defined by Bourdieu (1986/2011), social capital is the web of connections that exists between individuals who live and work in each community, which enables that community to operate efficiently. Examples of application of social capital in everyday life include parents from the same school may refer summer camps to one another, or parents from other schools may interact in some manner (for example, via social media such as Facebook groups) in order to exchange particular educational materials or to act as a group for the common interest of all members(for example, parents NGO groups that aim at advocating for education equity or social awareness for their children with special needs).

Cultural Capital

Bourdieu (1997) defined cultural capital as a person's education that gives them an edge in obtaining a better social standing in society, and he interpreted social capital as the use of social networks as a strategy to produce advantages over those who do not have the networks.

As suggested by Bourdieu (1986/2011), culture capital appears in several forms: objectified cultural capital represents materials such as books and other media that inform knowledge or actions; embodied cultural capital represents disposition and taste that guide ways of acting and thinking, and institutionalized cultural capital represents conferred capital such as academic credentials with associated benefits.

Using critical race theory, Yosso (2005) constructed community cultural wealth to challenge and expand standard cultural capital definitions developed by Bourdieu (1986). Yosso (2005) defines cultural capital as six types of capital that are not mutually exclusive or static but instead operate as dynamic processes that build on one another: aspirational, navigational, social, linguistic, familial, and resistant capital. In the study focusing on students of color's cultural resources, rather than the cultural resources of the majority group, Yosso (2005) expanded the definition of cultural capital by emphasizing the importance of community cultural assets and arguing that, in addition to the traditional forms of cultural capital as defined by Bourdieu, the distinct cultural resources of students of color should be recognized as cultural capital as well, allowing for a better understanding of their experiences as they navigate educational institutions.

Capital theories have been used to research the dynamics between parents and other significant stakeholders in their relationships, which were seen to impact parents views regarding their children's education experiences (e.g., De Gaetano, 2007; Williams & Sánchez, 2012). For example, Goldthorpe (2007) argued that, based on Bourdieu's cultural capital theory, which emphasizes the social class differences between school personnel and parents and the ways in which these differences can obstruct effective communication and mutual understanding, children of the upper class have an advantage in their understanding of the educational environment, while parents from lower classes found the school environment hostile, which had led to fewer parents' participation in school-based activities. Furthermore, the class disadvantages, as well as the consequences of less participation in school-based activities, function not simply as barriers because of lack of resources but also a difference in perceptions of sociocultural norms and practices containing the values and behavioral expectations by which the school operates (Robinson & Harris, 2014).

In comparison to other studies examining interactions between parents and other players in the society, including schools and teachers, the number of studies examining parents of children with special needs from a capital perspective is relatively small, and the following are several significant studies that shed significant light on the use and application of theoretical perspectives in this study.

3.3.3 Application of Bourdieusian theories in Studies of Parents of Children with Special Needs

Studies are frequently framed in Bourdieusian sociology with reference to contemporary dynamics of gender, class, and race. Drawing on Bourdieu's theorization on the interaction between structure and agent, researchers from various discipline identified the variegated ways in which parents of children with special needs interact with main players in special education, including schoolteachers and practitioners. These studies show that the concept of social capitalization strategies (capital theories) as well as the social-structured agents(habitus) developed by Pierre Bourdieu could be applied to multiple social fields

(Bystrianska, 2018) including immigration studies, parents and family studies. In the following subsections, I highlighted the insights that researchers across these areas gained that would have otherwise been missed.

- Studies of ethnic minority/immigrant parents

Guzmán and colleagues (2018) examine the accounts of Latino immigrant parent's perceptions of the contributions they made to their children's educational persistence by using the definition of community cultural wealth, an expanded definition of cultural capital incorporating critical racial theory developed by Yosso (2005). Their findings suggested that parental reports indicated that aspirational capital was the most often mentioned kind of wealth. Almost every parent in the sample reported a desire for their children to achieve a higher educational objective than they did for their children to have better careers.

Building on previous studies on immigrant families, Merali (2018) discussed the adaptation of capital in a cross-cultural transition scenario by describing a case of a large refugee family from Afghanistan to Canada. A thoughtful consideration of the interaction between pre- and post-immigration realities, including their disposition of cultural and religious identities, as well as the adaptation of advocacy to better fit the host society institutions, are found to be critical to successful economic, psychological, social, and cultural acculturation and adaptation in cross-cultural transition.

With data from children of immigrant families, Shen (2020) carried out longitudinal research to investigate the relationship between parental religion, socialization with individuals from different ethnic groups, and parental educational level with their children's adaption to the United States. The purpose of this research was to investigate the relationship between immigrant families' social capital and the adaptation of their second-generation children to the host society. The findings revealed that an immigrant family's socialization with individuals from other ethnic groups, as well as their presence in an ethnic community, was associated with their children's ability to integrate.

As stated above, although immigrant parents and ethnical minority parents share commonalities, they are different in many ways, including social cognition, ability to acquire capital, and their supporting networks, which are crucial regarding their dispositions and their ways of speaking, behaving, and thinking (Nyrio & Durst, 2021). Martinez-Cosio (2010) investigates the institutional reactions to the attempts of a Latino parent organization and an African American parent group to participate in a controversial urban school reform, and the author suggested that parental engagement in school reform is mediated by school districts' validation or dismissal of parents' social and cultural resources. The findings of this study suggested that the validation from institutions or structures may vary by the agent's class position and its skills at acquiring and activating its cultural resources.

- Studies of parents of children with special needs including ASD

Previous research on parental advocacy for children with ASD highlights the importance of cooperative engagement between parents and schools to provide optimal support for children with special needs, yet findings from such work suggest that parents are viewed as less-than-equal members in such collaborative efforts (McCabe, 2007; Su et al., 2020). Further, schools have been noted to fall short in providing adequate support to families with children on the autism spectrum, noting the extreme stress and challenges in advocating for their children’s rights to an inclusive education that allows for integration into regular classrooms (Cui, 2016; Hu, 2020).

Parents in the U.S. have long been noted to have trouble when communicating with various school actors (school leaders, teachers, special education professionals, etc.) about services for children in need of additional educational support (e.g., Koren et al., 1992; Nachshen, 2005; Porter & Walters, 2017). Such difficulty comes in various forms, including inequitable access to resources, lack of opportunities to share experiential knowledge, and a dearth of invitations for active participation, all of which present as a tangle of issues that warrant careful unpacking (Trainor, 2010). These observed inequities have endured in parallel with national policies like the Individuals with Disability Education Improvement Act (IDEA), which is purported to support all students with free education in the most inclusive approach possible (Zirkel, 2015). Active adherence to such national guidance has fallen short of stated goals, resulting in underdeveloped policies and practices at the local level and significant challenges for parents when attempting to enroll their children in regular classroom settings (McCabe, 2003; Yan & Deng, 2019).

Researchers have reported parents using strategies based on their personal connections in different scenarios and countries. For example, upper- and middle-class parents in the U.S. demonstrate stronger ties with school officials, hence gaining greater benefits for their children compared with those from working-class families (Coleman, 1988). As stated above, Bourdieu (1977/1986) characterized such societal privilege as social capital and parents were observed to activate their social network to gain social advantages or benefits for a variety of reasons including support for their children.

For example, Trainor (2010) applied this framework in their analysis of parents' utilization of social capital in advocating for their children. By interviewing participants from various cultural and social backgrounds, Trainor found that advocacy efforts were not always effective and that as parents gained more knowledge about the importance of social capital (e.g., using personal relationships with experts or teachers), advocacy efforts were more likely to succeed. Trainor also implied that the success of such advocacy efforts depends largely on the coherence between home and school; hence, teachers are less likely to dismiss parents and their children when they share cultural affiliations. Parents' reliance on expert opinions and advice from their social circles also played a significant role in the successful procurement of school services at school.

The uses of social capital in Chinese society reflect a different picture; researchers are generally interested in the use of guanxi, a Chinese idiom referring to refers to the art of networking and relationship building to achieve a particular goal (Liu, 2020; Xie & Postiglione, 2016), within a context heavily influenced by traditional, Confucian values and beliefs that emphasize the concept of "reciprocal obligations and indebtedness" (Liu, 2020, p. 454). Guanxi has a cultural connotation like social capital in that it is a form of power used to gain access to certain resources; however, it is distinct from social capital in that it also refers to a two-way obligation formed through exchange of favors to each other, which serves as an incentive for people in China to practice guanxi (Ruan & Chen, 2020).

Trainor (2010) also applied the capital theory by examining the utilization of different capitals by parents of children with special needs. In her research, Trainor asserted that cultural capital played a critical role in parents' advocacy for their children with special needs and that naming a disability reflected parents' knowledge of the special education system as well as their attitudes when they sought assistance, gained understanding from professionals, and navigated the complexities of unique educational processes.

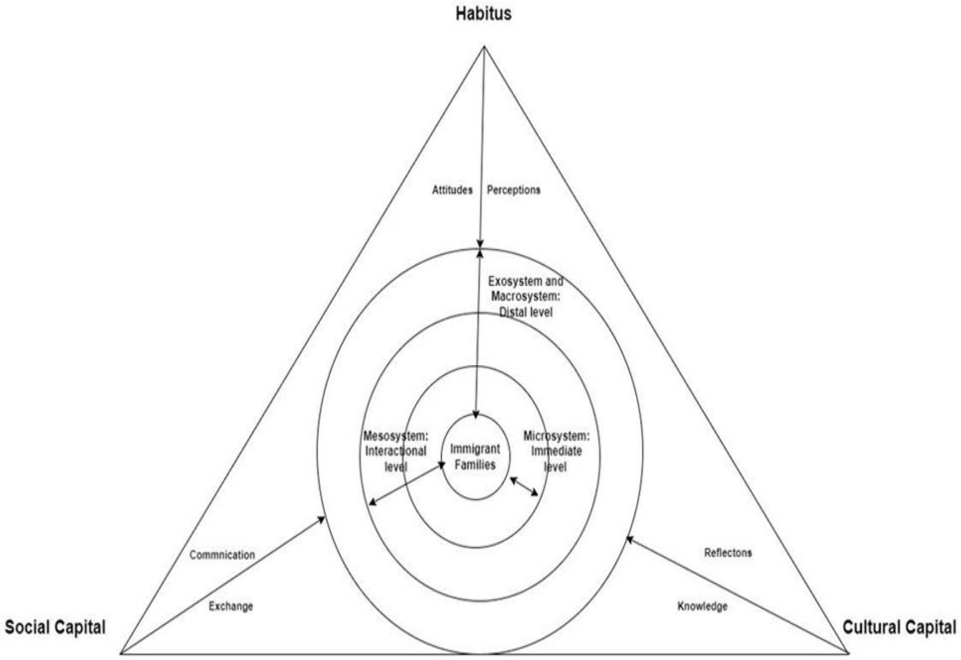
As Trainor (2010) stated, following the findings of research on parents' efforts of engagement and advocacy for their children with special needs, there has been a request for more parent training and information availability. However, in the field of special education, studies on the systematic barriers that have impeded parental advocacy have been less investigated. Compared to general education studies on equity and parent involvement via the theoretical perspectives from both the cultural and social capital, such as studies on resources parents and teachers value, acquire, and use as they interact with one another (Horvat et al., 2003; Lareau & Horvat, 1999), studies from the perspectives of parents of children with special needs while advocating for their children with disabilities from the perspectives of dynamics between agent and structure were less conducted. Although Trainor and her colleagues' work broadened our understanding of parental advocacy by framing it as an interaction between parents and other players in school institutions, similar studies on parental advocacy and participation from a sociological cultural and social capital perspective, as well as their relevance to parent participation and advocacy, have been scarce until now.

3.4 Conclusions

Bourdieu wrote in his work 'The Weight of the World: Social Suffering in Contemporary Society' published in 1999, that the personal narratives of subjective difficulties, tensions as well as contradictions one as an agent in society experiences often reflect the embedded contradictions of society as a structure. When an individual's habitus is adaptive to the environment, their habitus is not reflective to surrounding and the person will act like ‘a fish in the water’ (Bourdieu, 1977). However, once one moves to other social surroundings, e.g., immigrating to another country, the person’s original habitus formed in their home country will become reflexive because social norms and rules are unknown to them. Bourdieu’s theory of habitus and capital centers on the interpretation of what individuals need to learn to fit in and how individuals interact with other players by interpreting the objective social structure in a status of ‘a consciousness of awkwardness’ (Nyiro & Dursts, 2021). Furthermore, as suggested by other researchers, the transition from a home culture to a new host culture, compounding with the uncertainty and tension when immigrant parents feel that they belong to two contradictory cultures and traditions at the same time also led to greater reflexivity on their education-related choices for their children, with or without special needs (e.g., Trainor, 2010; Chiang, 2014).

In contrast to Bourdieu’s capital and habitus theories, which examine the ‘internal’ attributes of parents, the ecology theory of parenting views parental behavior as of interplay between parents and the ‘external’ societal system where they live. Therefore, the ecological theory of parenting (Bronfenbrenner,1979) would help interpret parents' experiences under a contextual ecological system in determining what constitutes effective services and interventions from the perspective of immigrant parents of children with ASD residing in the United States. The theoretical framework of both habitus, capital, and the ecological theory of parenting both contribute to obtaining a thorough knowledge of the nexus that constitutes the interviewed immigrant parents in society by concentrating on the link between agency and structure. This understanding is central to parents' perceptions of what constitutes a good service, because the quality of social service, whether paid or unpaid, must be viewed in the context of the interaction of a few interrelated domains of experience, beginning with the personal, progressing to the cultural, and concluding with the macro-societal (Nyrio & Durst, 2021). Figure 1 Theoretical framework provides an overview of the theoretical framework of this study.

Figure 1 Theoretical Framework Flowchart



↔ Interactions between immigrant families and other players in the multi-layered social contexts

→ Value (habitus and capitals) exchanges within the interactions

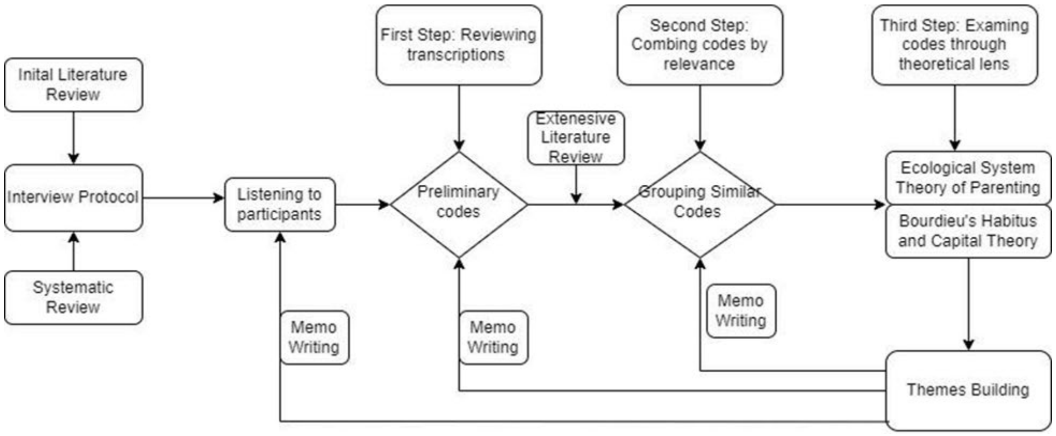
Chapter IV Methodology: Mixed-Methods Research Design: Dual Explorations Approach

4.1 Overview

This section provides a detailed account of my research process for this dissertation, which includes two different explorations. I believe a mixed-method research design may be a good fit in combining the strengths of divergent research approaches by offering the potential for linking qualitative and quantitative data in various ways (Pluye & Hong, 2014). Furthermore, as suggested by Feldon and Tofel-Grehl (2018), the advantages of a mixed-method research design include it could provide a powerful foundation for developing validity constructs that are meaningful across a wide range of data from different sources, a mixed-method research design would be helpful for achieving my research goals.

In this study, I used two complementary explorations to investigate the nature of parents' service choice under an explanatory theoretical framework: 1) I began by conducting a qualitative systematic review to investigate the factors that have been reported to influence immigrant parents' choice of ASD-related services. 2) Next, I developed interview protocols and surveys based on the findings of exploration 1, and I used interpretative phenomenological analysis to analyze the data from online surveys and interviews, employing the ecological system of parenting as the social contexts of immigrant parents and Bourdieu's capital and habitus theory as a lens to examine immigrant parents' navigation experience. 3) After that, I integrated and contrasted the findings of the two studies, and in the discussion section, I drew on the findings of the two studies to produce an interpretation and analysis of the navigation experience for service choices made by immigrant parents. Figure 2 Analytic Flowchart provides an overview of the methodology framework of this study.

Figure 2 Analytic Flowchart



4.2 Identify the Research Paradigm for This Study

A study's research paradigm must be determined to explain the philosophical framework that supports it before any concerns pertaining to the methodology of the study can be addressed (Guba & Lincoln, 1994). Furthermore, according to Denzin and Lincoln (2000), a paradigm can be understood within the philosophical anchors of ontology, epistemology, and methodology.

Ontology is a perspective on the form and character of reality which is concerned with what exists. Therefore, ontology inquiries tend to focus on the nature and operation of objects (Guba & Lincoln, 1994). On the other hand, epistemology focuses on the theory of knowledge and the nature of the interaction between the researcher and the study subjects about what can be known. As a result, epistemological problems are often concerned with how and what can be learned through observations (Willig, 2013). Finally, methodology refers to the approaches or processes utilized by the researcher to collect and analyze information that may be known (Crotty, 1998).

4.2.1 The First Exploration

In the first exploration, I chose a systematic review approach that incorporates ontological, epistemological, and methodological aspects.

The ontological part is centered on the explanation of the term CALD (Cultural and Linguistic Diversity) and its importance in understanding the shape and structure of reality in international migration contexts. In this systematic review, the term CALD is used to identify a community from a cultural, ethnic, religious, linguistic, or racial minority background defined within an international migration context (Dune et al., 2018). This term was used because it is more inclusive than solely race-based or language-based terms (e.g., it includes immigrants) and, therefore, may be better suited for addressing the challenges encountered by participants from diverse racial backgrounds (Bornstein, 2017).

Epistemologically, the main aim of this systematic review was to thoroughly investigate factors within the parenting ecological system, including the immediate levels (the microsystem, e.g., family, schools and peers), interactional levels (the mesosystem, such as interconnection between families and teachers or between the child's peers and the family), and distal levels (the exo-system and macrosystemic levels, i.e., links between social settings, such as parents' work, cultural contexts, ethnicity, traditions, and social-economic status) (Bronfenbrenner, 1979; Castillo et al., 2020). The aforementioned factors were further consolidated into two separate categories (Wilson et al., 2018; Standford et al., 2020): (a) implicit factors, which encompassed characteristics of families and children with ASD that were found to have a significant association with parents' selection of services for their children, and (b) explicit factors, which comprised the reasons provided by parents to clarify their decision-making process regarding service choices.

Lastly, I employed a systematic review technique based on the PRISMA protocol (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) protocol (Moher et al., 2009) and PRISMA 2020 checklist (Page et al., 2021). This protocol emphasizes the significance of an organized process for gathering and interpreting data.

4.2.2 The Second Exploration

According to Crotty (1998), a researcher's ontological and epistemological viewpoints are inextricably intertwined since meaning production includes portraying and understanding reality. My goal for the second exploration was to develop an understanding of ASD-related service providing from the perspective of immigrant parents by exploring their subjective experiences.

In the second exploration of my research, I tried to interpret data via the lens of Bourdieu's critical capital within the framework of Bronfenbrenner's social context. This means that I explored how contextual elements, such as parents' perceptions about autism, accommodations, and school services, might have influenced their experiences in selecting services. Furthermore, participants' meaning-making during interviews, as well as my personal understanding and interpretation of their responses, influenced the final data analysis.

Given these assumptions, this exploration most closely resembles an interpretivist-constructivist epistemology, which holds that reality is co-constructed by interactions between researchers and participants (Lincoln & Guba, 2000). According to them, reality is multi-layered, and people generate meaning depending on their perceptions, which in turn also changes their reality. This study is most suited to a qualitative approach within the interpretivist-constructivist paradigm, which strives to provide an in-depth explanation of a phenomenon and explain the lived experiences of immigrant parents about their interaction with their social surroundings and major players in the special education system.

Methodologically, the Interpretative phenomenological analysis method (IPA) was selected from all available qualitative research methods as the tool for analyzing data from interviews and surveys. According to Baker et al., (1992), IPA was inspired by the grounded theory method, and it is an interpretative variant of grounded theory because compared to traditional grounded theory, IPA has a double purpose: It is both data collection and qualitative data analysis method (Baker et al., 1992; Smith et al., 2009). Incorporating phenomenology and interpretation, IPA focuses on the lived experience of participants and shares the goals of idiographic phenomenology, which offers a deep investigation of parts of the reflective personal and subjective perspective of individual experiences. As suggested by Merleau-Ponty's philosophy, people's perceptions must always be interpreted in the context of the ground where they happen (Sohn et al., 2017). As such, in this study, to understand the immigrant parents' perspectives toward services and practices, I used the Interpretive phenomenological analysis (IPA) method by giving careful attention to what emerges in participants' narratives regarding their cultural beliefs to concepts such as effective service and practice.

Instead of developing a new theory explaining how immigrant parents interpret their experiences of service and practices for their children with ASD, this is a study aiming at aim at unfolding meanings hidden underneath the narratives of participants' experiences (Sohn et al., 2017). It is proposed that IPA researchers utilize open-ended interview methods to elicit descriptions of participants' life experiences without relying on pre-set values.

Researchers noted that IPA searches for deeper meanings and relationships in the data that people may not recognize on their own (Kirn et al., 2014). In addition, the interpretative approach to phenomenology employs sophisticated theoretical knowledge and holds that the researcher's subjectivity cannot be eliminated from the analysis, which is aligned with my positioning as both an insider and outsider at the same time in this study. In conclusion, IPA is appropriate for this study because it goes one step further than phenomenology (participant accounts) and aids me, as a researcher, in my endeavor to report on and analyze the participant's experience by taking into consideration my own biases and worldviews during interpretation.

4.3 Researcher's Positionality Toward the Study Target

Within the context of qualitative research, there has been a great deal of discussion on the question of whether a researcher should be a member of the population that they are investigating, and what implications or effects the 'insider' vs 'outsider' position of researchers has had on studies. In their study, Dwyer and Buckle (2009) concluded that there are advantages and disadvantages associated with having either status as a researcher and that dichotomous labeling confines a researcher to being classified as possessing just one of the two positions. In addition, they suggested that there are statuses in between the two that allow both viewpoints to be maintained by one researcher, a possibility made possible by Fay's (1996) assertion that self-understanding and other understanding are mutually dependent to each other.

I consider myself within the space between the insider and outsider researcher status. Firstly, I am a mother of a 13-year-old boy who was diagnosed with ASD when he was 4, and we moved to the United States when he was 6. I, therefore, as the parent of a child with ASD, have first-hand knowledge of the challenges experienced by families with children with special needs and a natural connection with the parents' community, which is built through shared experiences. I also identify myself as an "outsider," a person who is neither a U.S. immigrant nor currently undergoing an immigration process. In addition, as a researcher in special education, I take a non-hierarchical position toward the uniqueness of all participants, so seeking to prevent making assumptions about people based on the concept of universal law (Cooper, 2009). As a result, I consider myself an outsider since I am conscious that my comprehension of another person can never be perfect.

As suggested by Breen (2007), insider researchers are frequently confronted with methodological and ethical issues that are largely irrelevant to outsider researchers. In order to manage the challenges of locating myself in the space between, particularly those related to the insider position, I have used reflexivity throughout the research process to consider the methodology and ethical challenges that may arise and planned carefully to address research questions. According to Breen (2007), one of the obstacles of being both an insider and a researcher is the possibility that participants may believe the researcher already knows the answers. The use of reflection throughout the research enabled me to recognize emotions and reactions that developed throughout the process of making meaning of the data gathered, allowing me to step back from the phenomena and reflect on my own approach, expectations, and presumptions.

4.4 Development of the Research Questions

Based on my positionality as both an insider(parent) and outsider(researcher) in this research, as well as the literature review of immigrant parents' perspectives on what constitutes a good service based on their own experiences. I was curious about their understanding of good educational practices and resources as well as factors that influence their decisions to choose school-based interventions and/or services and formed the research questions as below:

As I stated under section 1.1, the general research questions are: What do we know, and what do we need to learn about the perspectives and experiences of immigrant parents in the U.S. who have children with ASD?

Along with the general research questions, the line of Inquiry for Exploration 1 (Systematic Review) is:

- What have researchers learned so far about this population?
- What do we still need to know about this population?

The preliminary findings of this initial exploration were crucial in the development and refinement of the second line of inquiry, which led to the subsequent second qualitative interview study. These preliminary findings highlighted characteristics from earlier studies that influenced parents' service choices within a complex interplay between parents and other stakeholders across multiple social domains, as defined by Bronfenbrenner (1979). As I dug deeper into the complexities of habitus and capital theory to gain a better understanding of how these notions appear in the context of special education services and thus influence immigrant parents' decision-making processes, I realized the importance of connecting what I already know from previous studies with individual live experiences and their narratives. The second line of inquiry for the second exploration is as follows, based on the findings of the first exploration:

- What goals or expectations did immigrant parents have about their children in terms of special education services in the US?
- What are the features of practitioners/professionals/services that immigrant parents find most appealing?
- What are the main concerns/considerations that immigrant parents have while deciding on an intervention, service, or agency?
- What changes, if any, are observable in immigrant parents' perceptions of what constitutes intervention service of quality for their children?

4.5 Evaluation of the Quality of This Study Design

There are a variety of views on the criteria that might be used to evaluate qualitative approaches; Denscombe (2002), for instance, proposed a few characteristics that identify successful social research. These include the contribution of new information, the use of legitimate data acquired and used in a justified manner, and findings from which generalizations may be drawn and applied to other fields. Also, studies have indicated that the researcher's personal positions and attitudes play a crucial part in a high-quality social study. In an early study, Henwood and Pigeon (1992) proposed a set of criteria for evaluating quality in greater detail. They suggested that researchers should stay close to the collected data, create integration with theories, consistently use documenting reflexivity, and emphasize the generalization significance of the study's findings. Tong and colleagues (2007) further summarized and established a 32-item checklist titled "consolidated criteria for reporting qualitative research" (COREQ), which comprises three domains: research team and reflexivity, research design, and results. According to the researchers, COREQ is a complete checklist that includes all relevant study design components that must be disclosed in a social study. The criteria provided in the checklist may assist researchers in describing essential components of the research team, study methodology, study setting, results, analyses, and interpretations. Although the research has diverse focus and standpoints due to varying disciplines, they did have several characteristics in common. For example, they all placed an emphasis on the importance of subjectivity, reflexivity, social validity, enough data, and adequate interpretations (Morrow, 2005).

To be mindful of various criteria for assessing the quality and credibility of the present study, I drew on guidance derived from all these studies, which suggested that the credibility and quality of a qualitative study depend on the depth of interpretation, the scope of the data source, and the suitability and sufficiency of the alignment between research questions and research method. In the following sections for study 1 and study 2, I will return to these criteria to illustrate how this study ensured the quality of its research data.

Chapter V Study 1: A Systematic Review of Factors Related to Minority/Immigrant Parents’ Service Decisions for Their Children with ASD

5.1 Overview: Rationale for the Systematic Review

When it comes to services for children with ASD, as previously stated, there are studies that use both quantitative (such as a randomized controlled trial or a survey) and qualitative methods(interviews) to explore parents' perceptions of and choices among different interventions and service options when they are seeking services for their children with ASD.

Because so few studies have been conducted specifically on immigrant parents of children with ASD, there is a gap in the literature.

Additionally, there has not yet been a systematic review conducted to synthesize studies that have quantified the relationship between variables of immigrant or minority parents and their choices of services. I conducted a systematic review in accordance with the PRISMA guideline (Moher et al., 2009) and presented the relationship between immigrant parents' choice of intervention and variables such as demographic characteristics of themselves and their children with ASD, among other things. An inter-rater agreement was conducted on the selection of studies with the help of another graduate student who will solely be involved in the selection of studies for meta-analysis and will not be involved in any other aspects of this study.

As suggested by Hallinger (2013), although the systematic approach is more functional in nature, it is never value-neutral and recognizes the possibility of critical perspective as the lens used in the systematic review was pre-determined by the researcher. This approach to research explored how the understanding of a phenomenon is founded in the inter-subjective social world, and it concealed the assumption that there is intentional consciousness, which forms the driving force in constituting an object's meaning (Ajiboye, 2012). Therefore, even though the purpose of this study is to understand a social phenomenon by exploring the commonalities that are found in the subjective life worlds of more than one actor, which is an effort to provide a more objective description and understanding of a subjective experience (Shaw & Connelly, 2012), as a researcher, I must acknowledge that owing to the small sample size and the subjective nature of my cognition and knowledge of the participant's perceptions, I may have overlooked or misinterpret some of the outcomes of earlier studies while using systematic analysis to synthesize those results.

As stated above under section 4.4, the primary goal of this research is to better understand the viewpoints and experiences of immigrant parents in the United States who have children with ASD. Under this main line of inquiry, the research questions for the first exportation, which is the systematic review, involve two key questions: first, an examination of existing knowledge about this specific population, and second, an exploration of the gaps in our understanding, highlighting what remains to be learned about their unique experiences and challenges.

5.2 Method

The systematic review was conducted following the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) protocol (Moher et al., 2009) and PRISMA 2020 checklist (Page et al., 2021). The present review was also registered on the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY). The registration number of the systematic review in INPLASY is 2022100019.

5.2.1 Inclusion and Exclusion Criteria

Included studies reported on characteristics related to service utilization or stated reasons for selecting treatments/services for children with ASD. The studies that were included in the present review study met the following criteria.

1. Participants included racial/ethnic and language minority mothers, fathers, or children’s primary caregivers.

2. Child participants in the studies had a primary diagnosis of ASD.
3. The findings included at least one factor that impacted parents' service choices. Studies only about the effectiveness of treatments or services were not included.
4. Types of services were not limited to certain interventions or treatment types (e.g., recreational or respite services and school-based services).
5. Only peer-reviewed empirical studies were included. Review or discussion papers, meta-analyses, systematic qualitative reviews, conference papers, and dissertations were excluded.

5.2.2 Search Strategy

A systematic search of the databases PsycINFO, ERIC, and Web of Science was first conducted in November 2021 and repeated in July 2023. Initially, the search scope excluded studies published prior to 2000 and included *surveys* or *randomized controlled trials* (RCT) in its search terms due to the desire for more recent and higher-quality data. To include as many qualified studies as feasible, the two authors expanded the search scope by 1) removing the publication year restriction and 2) removing the search term *survey* or *RCT*. The final search terms were *(parents* or *mother* or *father* or *families* or *family)* and *(ASD* or *autism)* and *(intervention* or *service* or *therapy)* and *(perspectives* or *preference* or *choice of intervention* or *choice* or *attitudes),* and *(immigrant* or *minority).* A total of 31 studies were included in the study for a systematic review. **Attachment 1 Table of Studies** listed all studies included and excluded in systematic review in the process.

5.2.3 Quality Assessment

The quality of all included studies was evaluated using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al., 2004). At the commencement of the project, a quality checklist was developed. The quality plan included evaluation criteria for research quality. The rater assigned a score of 2 (yes), 1 (half), or 0 (no) for all components of the study. A summary score for each research project was calculated by dividing the scores by the maximum possible score under the column "Quality Score" of Table 1. The possible range of ratings was from 0 to 1, with higher values indicating more strategic excellence. Due to the exploratory nature of the survey and the limited number of qualified studies, the authors decided not to set up a threshold or a minimum score for studies to be included, as other researchers have (e.g., Wilson et al., 2018); instead, the assessment was completed to provide a broad indication to readers about the strengths and weaknesses of each study in writing and the relevance to the topics of the review.

In addition, to ensure that the quality and accuracy of each study included in the study met the criteria outlined on the checklist, the second author was trained and guided by the first author regarding the purpose of the study, and the second author audited and evaluated the studies using the following procedure: the second author randomly picked and graded 20% of the studies (i.e., six studies) using the random number generator. Initial inter-rater agreement was calculated by dividing agreed item scores by total item scores and multiplying the result by 100. The level of agreement needed to be at least 95% for quantitative research and 100% for qualitative studies. Discrepancies in ratings were resolved through discussions and re-evaluations of the papers.

5.2.4 Data Extraction and Synthesis

Data were extracted on study characteristics: publication year, design, data source, methodology, treatment type investigated, sample size, age of the children, and key findings. Data extraction was completed by the first author. The initial inter-author agreement regarding study characteristics was calculated in a similar manner as was used for study scoring: by dividing the number of agreed studies by the total number of studies checked and multiplying by 100. The agreement was 95%. Discrepancies in data extraction were resolved through discussion and re-checking the papers.

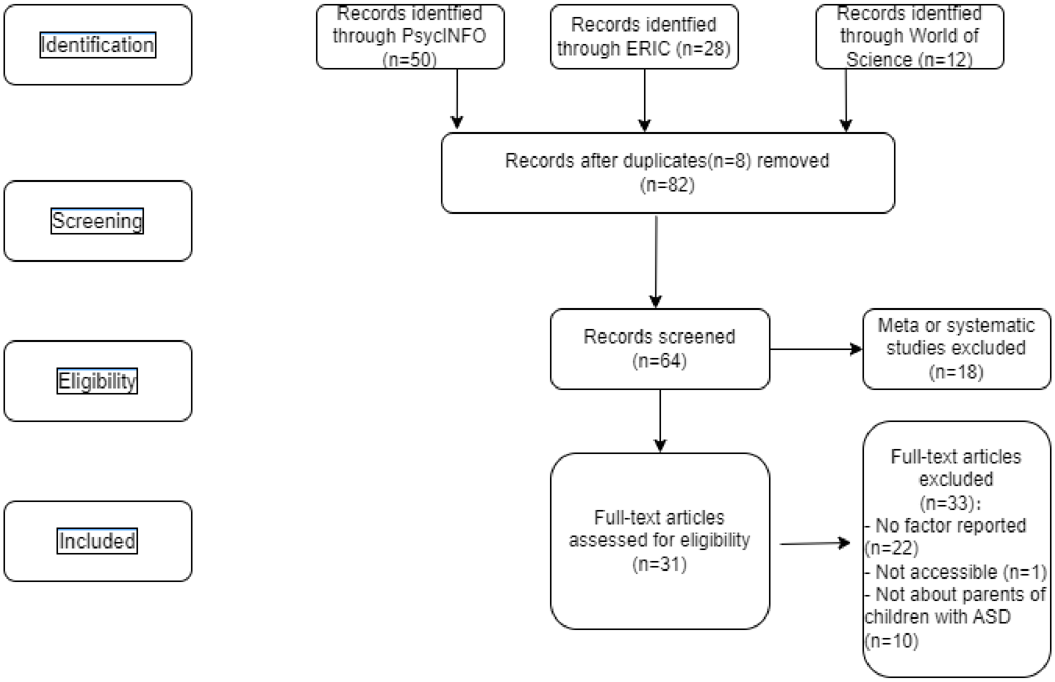
Studies were examined to identify explicit and implicit factors that were investigated for associations with parents' choices of services/interventions/practices for their children with ASD. For qualitative studies, this was achieved by listing the key themes identified by the authors. For quantitative studies, statistics with $p < .05$ were considered significant, and key themes or percentages relating to declared reasons were extracted.

5.3 Results

5.3.1 Search Results

All studies used surveys or interviews to determine parents' perspectives toward services or intervention treatment. Initially, the database search produced 111,677 records; after narrowing it down to peer-reviewed articles that contain search terms in the abstract, the search produced 100 results. With duplicates (8) removed, 82 records remained. After excluding meta-analyses, systematic reviews, and literature reviews (18 in total), 64 results remained. After excluding the studies that were not accessible or not directly related to the topic of the study (33), 31 studies were identified to be included in this systematic review. The search result process was guided by the PRISMA Flow Chart (Figure 3). All titles and abstracts were screened for eligibility by the first author, and the second author rescreened 20% of abstracts (6). The agreement between screeners reached 100%. Among the 31 included studies, five were quantitative studies, 24 were qualitative studies, and two used mixed methods.

Figure 3. PRISMA Flow Chart Summary of Search Result



5.3.2 Descriptions of the Results

- Overview

The 31 included studies revealed a total of 21 factors related to CALD minority parents' experiences with service options for their children with ASD. The most reported explicit factor was the perceived home cultural values/attitudes toward ASD (Fong et al., 2022; Fox et al., 2017; Habib et al., 2017; Kang-Yi et al., 2018; Khanlou et al., 2015; Kim & Dababnah, 2022; Millau et al., 2018; Perepa, 2014; Ravindran & Myers, 2013; Sakai et al., 2019), and the most reported explicit factor was the demographic information of parents (gender, race, educational background, and immigration status; Bilaver & Havlicek, 2019; Birkin et al., 2008; Jashar et al., 2019; Perepa, 2014; Pondé & Rousseau, 2013; Millau et al., 2018; Zuckerman et al., 2015). Among the 20 factors, parents' understanding/knowledge/attitudes toward ASD were reported as both implicit (Bilaver & Havlicek, 2019; Zuckerman et al., 2015) and explicit (Birkin et al., 2008; Chlebowski et al., 2018; Fox et al., 2017; Kang-Yi et al., 2018; Ravindran & Myers, 2013; Rivard et al., 2019; Stahmer et al., 2019).

Tables 2, 3, and 4 provide an overview of the characteristics and findings of the included studies. Table 2 provides an overview of the included studies' characteristics, Table 3 provides an overview of explicit and implicit factors reported in all 31 included studies, and Table 4 provides a summary of all 20 factors according to their respective positions at the immediate (microsystemic), interactional (mesosystemic), and distal (exosystemic and macrosystemic) parenting ecological system levels (Bronfenbrenner, 1979). The categorization of factors was conducted based on conceptualizing the parental ecological system and its utilization in prior scholarly investigations (e.g., Hong et al., 2019; Castillo et al., 2020).

Table 2. Characteristics of the Included Studies

Study Characteristics	Range	Number of Studies and Percentages
Sample Size (n)		
	< 50	22 (71%)
	50–100	3 (10%)
	200–300	1 (3%)
	> 300	5 (16%)

Culturally and Linguistically Diverse (CALD) Minority Parents (n)		
	< 50	24 (78%)
	50–100	2 (6%)
	> 300	5 (16%)
Service/Intervention Investigated		Number of Times Mentioned
	School-based services	20
	General clinical services	16
	Diagnostic services	5
	Behavior-based services/interventions	4
	Community-based services	2
	Early intervention program	2
	Sensory integration therapy	1
	Cognitive-based therapy	1
	Genetic treatment	1

Table 3. Explicit and Implicit Factors in the Included Studies:

	Number of Studies n (%)	Authors and Methods of Studies (n)
Explicit Factors (n = 15)		
Perceived home cultural values/attitudes toward ASD	10 (32%)	Qualitative studies (n = 10): Fong et al., 2022 Fox et al., 2017 Habib et al., 2017 Kang-Yi et al., 2018 Khanlou et al., 2015 Kim & Dababnah, 2022 Millau et al., 2018

		Perepa, 2014 Ravindran & Myers, 2013 Sakai et al., 2019
Language barriers	8 (26%)	Mixed method (n = 1): Birkin et al., 2008 Qualitative studies (n = 7): Fong et al., 2021 Hubert, 2006 Huer et al., 2001 Khanlou et al., 2015 Kim & Dababnah, 2022 Montoya et al., 2022 Shanmugarajah et al., 2022 Stahmer et al., 2019
Parents' understanding/knowledge/attitudes toward ASD⁑	7 (23%)	Mixed studies (n = 1): Birkin et al., 2008 Qualitative studies (n = 6): Stahmer et al., 2019 Chlebowski et al., 2018 Fox et al., 2017 Kang-Yi et al., 2018 Ravindran & Myers, 2013 Rivard et al., 2019
Partnership between parents and professionals	7 (23%)	Mixed studies (n = 1): Jashar et al., 2019 Qualitative studies (n = 6): Chlebowski et al., 2018 Fong et al., 2021 Hubert, 2006 Pearson et al., 2020 Sakai et al., 2019 Stahmer et al., 2019
The way services/interventions were delivered (pedagogy, video, online or in-person,	7 (23%)	Mixed studies (n = 1): Birkin et al., 2008 Qualitative studies (n = 6): Fong et al., 2022

community-based or clinic-based, detailed guide to services, parents' participation)		Hubert, 2006 Kizildag et al., 2022 Xu et al., 2022 Fong et al., 2021 Chlebowski et al., 2018
Parents' knowledge of the special education system	6 (19%)	Qualitative studies (n = 6): Huer et al., 2001 Khanlou et al., 2015 Montoya et al., 2022 Pearson et al., 2020 Pondé & Rousseau 2013 Stahmer et al., 2019
Social isolation	5 (16%)	Qualitative studies (n = 5): Fong et al., 2022 Hubert, 2006 Pondé & Rousseau 2013 Rivard et al., 2019 Stahmer et al., 2019
Perceived host cultural values toward ASD	4 (13%)	Qualitative studies (n = 4): Chlebowski et al., 2018 Fong et al., 2021 Perepa, 2014 Ravindran & Myers, 2013
The stigma attached to ASD	4 (13%)	Qualitative studies (n = 4): Fong et al., 2021 Fong et al., 2022 Fox et al., 2017 Stahmer et al., 2019
Parents' pre-existing obligations/burdens from work and life	3 (9%)	Mixed studies (n = 1): Birkin et al., 2008 Qualitative studies (n = 2): Hubert, 2006 Stahmer et al., 2019
Support from family members	3 (9%)	Qualitative studies (n = 3): Hubert, 2006

		Pondé & Rousseau, 2013 Stahmer et al., 2019
Out-of-pocket cost	3 (9%)	Qualitative studies (n = 3): Fong et al., 2021 Hubert, 2006 Kizildag et al., 2022
Waiting time for services	2 (6%)	Mixed studies (n = 1): Birkin et al., 2008 Qualitative studies (n = 1): Rivard et al., 2019
Immigration status (time, insecurity of being an immigrant)	2 (6%)	Qualitative studies (n = 2): Huer et al., 2001 Stahmer et al., 2019
Parental advocacy	1 (3%)	Qualitative studies (n = 1): Stahmer et al., 2019
Implicit Factors (n = 6)		
The demographic information of parents (gender, race, and educational background)	7 (23%)	Mixed studies (n = 2): Jashar et al., 2019 Birkin et al., 2008 Quantitative studies (n = 2): Bilaver & Havlicek, 2019 Zuckerman et al., 2015 Qualitative studies (n = 3): Pondé & Rousseau, 2013 Millau et al., 2018 Perepa, 2014
Parents' social and economic status (income)	2 (6%)	Quantitative studies (n = 1): McLeod & DiSabatino, 2019 Qualitative studies (n = 1): Chen et al., 2013
Parents' understanding/knowledge/attitudes toward ASD ⁑.	2 (6%)	Quantitative studies (n = 2): Bilaver & Havlicek, 2019 Zuckerman et al., 2015

Age of children	1 (3%)	Quantitative studies (n = 1): McLeod & DiSabatino, 2019
Parents’ concerns about their children’s development	1 (3%)	Quantitative studies (n = 1): Solgi et al., 2022
Private insurance	1 (3%)	Quantitative studies (n = 1): Bilaver & Havlicek, 2019

⁑ Factors reported both as implicit and explicit factors in studies.

Table 4. Summary of Findings Across the Ecological Parenting System

Layers of the Ecological System of Parenting	Implicit/Explicit	Number (Percent) of Studies
Within the Immediate System of Parenting (Microsystem)		
Parents’ attitudes about and understanding of ASD	Implicit and explicit	9 (29%)
Parents’ knowledge of the special education system	Explicit	6 (19%)
Support from family members	Explicit	3 (9%)
Age of children	Implicit	1 (3%)
Parents’ concerns about their children’s development	Implicit	1 (3%)
Within the Interactional Parenting System (Mesosystem)		
Language barriers	Explicit	8 (26%)
The way services/interventions were delivered	Explicit	7 (23%)
Partnership between parents and professionals	Explicit	7 (23%)

Out-of-pocket cost	Explicit	3 (9%)
Waiting time for services	Explicit	2 (6%)
Parental advocacy efforts	Explicit	1 (3%)
Private insurance	Implicit	1 (3%)
Within the Distal System (Exo-system and Macrosystem)		
Perceived home cultural attitudes toward ASD	Explicit	10 (32%)
The demographic information of parents (gender, race, educational background)	Implicit	7 (23%)
Social isolation	Explicit	5 (16%)
Stigma and discrimination	Explicit	4 (13%)
Perceived host cultural attitudes toward ASD	Explicit	4 (13%)
Parents' pre-existing obligations/burdens from work and life	Explicit	3 (9%)
Immigration status (time, insecurity of being an immigrant)	Explicit	2 (6%)
Parents' social, and economic status (income)	Implicit	2 (6%)

- Within the Immediate System

There are three implicit and three explicit factors that were categorized under the immediate system of parenting/microsystem because they all relate to the immediate circumstances that may have influenced the behavior and decisions of parents (Hong et al., 2019). Parents' attitudes about and understanding of ASD were reported as both explicit and implicit factors among these factors.

1. Parents’ Attitudes About and Understanding of ASD

There were nine studies reporting parents’ attitudes about or/and understanding of ASD as an indicator or finding in terms of its association with service choices. Among them, there are two quantitative studies (Bilaver & Havlicek, 2019; Zuckerman et al., 2015), one mixed study (Birkin et al., 2008), and six qualitative studies (Stahmer et al., 2019; Chlebowski et al., 2018; Fox et al., 2017; Kang-Yi et al., 2018; Ravindran & Myers, 2013; Rivard et al., 2019).

Birkin et al. (2008) reported in the qualitative analysis section that parents’ knowledge of ASD is one of the self-reported factors that have impacted their choices of services. Bilaver and Havlicek (2019) and Zuckerman et al. (2015) reported statistical significance between parents’ perception of ASD and their choice of services. The qualitative studies included in this analysis identified parents' understanding or knowledge of ASD as a contributing factor in facilitating access to services (Ravindran & Myers, 2013; Rivard et al., 2019). Conversely, the studies also highlighted a lack of parents' understanding of ASD as a barrier to accessing services (Chlebowski et al., 2018; Fox et al., 2017; Stahmer et al., 2019; Kang-Yi et al., 2018).

2. Parents’ Knowledge of the Special Education System

A total of six qualitative studies (Huer et al., 2001; Khanlou et al., 2015; Montoya et al., 2022; Pearson et al., 2020; Pondé & Rousseau, 2013; Stahmer et al., 2019) documented that parents possessing adequate knowledge about the special education system in their respective countries serves as a facilitating factor in enabling them to access school-based services for their children.

3. Support From Family Members

Three qualitative studies identified a dearth of familial support as a hindrance to receiving services (Hubert, 2006), whereas the assistance provided by other family members has been recognized as a facilitator in accessing services (Pondé & Rousseau, 2013; Stahmer et al., 2019).

4. Age of Children

One study highlighted the age of children as a significant factor influencing parents' selection of services. According to a quantitative study conducted by McLeod and DiSabatino (2019), it was shown that parents of older children exhibited a considerably lower tendency to perceive their child's illness as transient and were less inclined to assume that symptoms may be alleviated by treatment.

5. Parents' Concerns About Their Children's Development

According to a recent quantitative study conducted by Solgi et al. (2022), it was shown that parents who voiced concerns about their children's developmental progress were more inclined to seek evaluations for their children inside early intervention programs.

- Within the Interactional System

Within the interactional mesosystem, a total of six explicit components and one implicit factor have been identified. These factors pertain to the interactions between parents and other supportive systems that assist families and their children diagnosed with ASD.

1. Language Barriers

Language barriers have been identified as a significant obstacle in the experiences of parents when seeking services, as reported in a total of seven qualitative studies (Fong et al., 2021; Hubert, 2006; Huer et al., 2001; Khanlou et al., 2015; Kim & Dababnah, 2022; Montoya et al., 2022; Shanmugarajah et al., 2022; Stahmer et al., 2019), along with one mixed-method study included in the qualitative section (Birkin et al., 2008).

2. The Way Services/Interventions Were Delivered

Seven research studies examined the impact of service delivery on parents' engagement in services (Fong et al., 2022; Hubert, 2006; Kizildag et al., 2022; Xu et al., 2022; Fong et al., 2021; Chlebowski et al., 2018; Birkin et al., 2008). As an example, Birkin et al. (2008) found in their qualitative analysis that incorporating video technology in service provision was linked to a decrease in parents' inclination to engage. Fong et al. (2021) identified the absence of a comprehensive service manual as a significant obstacle to service accessibility.

3. The Partnership Between Parents and Professionals

There are a total of seven qualitative studies, which include one mixed method study with a qualitative section, that have examined and recorded the impact of positive communication between parents and service providers on parents' engagement and utilization of services (Jashar et al., 2019; Chlebowski et al., 2018; Fong et al., 2021; Hubert, 2006; Pearson et al., 2020; Sakai et al., 2019; Stahmer et al., 2019).

4. Out-of-Pocket Cost

Among all included studies, three qualitative studies reported out-of-pocket costs as one of the factors that impeded service access to children with ASD (Fong et al., 2021; Hubert, 2006; Kizildag et al., 2022). For example, Fong et al. (2021) reported that the increased amount of out-of-pocket cost is a barrier for Korean immigrant families to get access for their children.

5. Waiting Time for Services

Two studies, conducted by Rivard et al. (2019) and Birkin et al. (2008), have identified the length of time of waiting for services as a prominent factor influencing parents' experiences while navigating the special education system and seeking appropriate services for their children diagnosed with ASD. The participants in a quantitative study conducted by Birkin et al. (2008) identified the waiting length for diagnostic services as a barrier ($p < 0.01$). Similarly, Rivard et al. (2019) discovered in their qualitative study that the extended waiting time to receive services was perceived as a barrier.

6. Parental Advocacy Efforts

The study conducted by Stahmer et al. (2019) is the only qualitative investigation that proposes a link between the advocacy efforts of immigrant parents and their ability to get services.

7. Private Insurance

According to a quantitative study conducted by Bilaver and Havlicek (2019), there was a strong correlation between possessing private health insurance and decreased likelihood of utilizing non-school services ($p = 0.034$).

- Within the Distal System

There are six explicit factors and two implicit factors that encompass both formal and informal social structures. These social structures do not directly provide services, but they indirectly impact families and their decisions regarding services. This influence is exerted through the social environments in which families are situated.

1. Perceived Home Culture’s Attitudes Toward ASD

Of included studies, 10 qualitative studies suggested perceived traditional/home cultural attitudes toward ASD as an important factor that might have affected parents’ choice of services (Fong et al., 2022; Fox et al., 2017; Habib et al., 2017; Kang-Yi et al., 2018; Khanlou et al., 2015; Kim & Dababnah, 2022; Millau et al., 2018; Perepa, 2014; Ravindran & Myers, 2013; Sakai et al., 2019).

All 10 studies yielded consistent findings indicating that the perception of traditional cultural perspectives on ASD may impede individuals' ability to avail themselves of necessary assistance. Rivard et al. (2019) found a correlation between parents' attitudes about ASD and their cultural backgrounds, with these opinions subsequently impacting parents' utilization of ASD-related services. According to Fox (2017), there exists a reluctance among Somali immigrant parents in the UK to seek services, due to the prevailing unfavorable perception of ASD within the Somali community.

2. Parents’ General Demographic Information

Among the four quantitative studies that examined parents' background information as the variable of interest, two quantitative studies (Bilaver & Havlicek, 2019; Zuckerman et al., 2015) identified a statistically significant relationship between ethnicity and service selection. Additionally, two mixed-method studies (Jashar et al., 2019; Birkin et al., 2008) reported statistically significant associations between ethnicity and parents' inclination to utilize available services. In the three qualitative research studies, Millau et al. (2018) and Perepa (2014), together with Pondé and Roussean (2013), have highlighted parents' ethnicity and gender as significant factors that influence the selection of services by parents for their children diagnosed with ASD.

3. Social Isolation

Social isolation emerged as a significant barrier encountered by parents in their utilization of available services for their children, as indicated by five qualitative research (Fong et al., 2022; Hubert, 2006; Pondé & Rousseau, 2013; Rivard et al., 2019; Stahmer et al., 2019). Pondé and Rousseau (2013) proposed that establishing a relationship between immigrant moms of children with ASD and their cultural community in Canada is of utmost importance in facilitating their access to necessary assistance.

4. Stigma and Discrimination

Four qualitative studies revealed stigma and discrimination associated with ASD as one of the reported possible reasons why service access was hindered (Fong et al., 2021; Fong et al., 2022; Stahmer et al., 2019; Fox et al., 2017). For example, Fong and colleagues (2021, 2022) suggested that stigma and discrimination are the predominant community attitudes toward autism and developmental disorders in the Korean American community; similarly, Fox et al. (2017) emphasized that it is essential to minimize the stigma associated with ASD and to encourage Somali immigrant families to seek care for their children with ASD without delay.

5. The Perceived Host Culture’s Attitude Toward ASD

The concept of perceived host cultural attitudes about ASD pertains to the subjective perceptions of parents about the prevailing social culture surrounding ASD in the country in which they originally lived. The review incorporates four qualitative studies (Chlebowski et al., 2018; Fong et al., 2021; Perepa, 2014; Ravindran & Myers, 2013) that indicate a connection between parents' perceptions and their cultural background, as well as the prevailing representations in the host society. This leads to the development of a hybrid knowledge reconstruction that is characteristic of the migrant experience, as proposed by Fong et al. (2021). Despite the fact that Korean immigrant parents have relocated from Korea to Canada, their adherence to traditional beliefs regarding disability continues to have a negative impact on their decision-making process and reduces their willingness to seek services due to the stigma associated with ASD.

6. Parents’ Pre-Existing Obligations/Burdens from Work and Life

One mixed-method study (Birkin et al., 2008) and two qualitative studies (Hubert, 2006; Stahmer et al., 2019) have examined the influence of parents' pre-existing obligations, such as their daily work schedule, on their decision to utilize services. These studies found that parents perceive the service as an additional burden that will make it challenging for them to manage their various responsibilities effectively.

7. Immigration Status

The influence of immigration status on parents' experience of services was found as a significant factor in two qualitative studies, conducted by Huer et al. (2001) and Stahmer et al. (2019). Huer et al. (2001) proposed that parents who have resided in a foreign country for an extended duration exhibit higher levels of satisfaction and openness toward services provided for their children. Conversely, Stahmer et al. (2019) posited that the challenges associated with being an immigrant hinder parents from actively seeking services for their children.

8. Parents’ Social and Economic Status

Parents' income was identified as one of the implicit elements in this study, as indicated by both quantitative and qualitative studies. According to a study conducted by Chen et al. (2013), it was shown that Asian parents with lower incomes demonstrated a decreased inclination toward utilizing services. Similarly, McLeod and DiSabatino (2019) discovered that parents with greater incomes were more inclined to hold the belief that their child's condition could be mitigated or prevented by service or therapy.

5.4 Conclusions of Study 1

5.4.1 What We Know Now

The purpose of this systematic review is to synthesize the implicit factors and the explicit factors which were reported as significantly associated with service choices of CALD minority parents for their children with ASD and understand them through the context-based, three-layered nested structure of the parenting ecological system (Bronfenbrenner, 1979). According to the definitions of implicit and explicit factors, (Dardennes et al., 2011; Erba, 2000; Frame & Casey, 2019) and the parenting ecological system theory (Bronfenbrenner, 1979), factors that fall into the immediate parenting layer were both explicit (3) and implicit (3), whereas those that fall into the interactional and distal layers are mostly explicit factors (12), with a few implicit factors (3). Six out of the 20 factors that emerged from 31 included studies are implicit factors that may have influenced the service choices of CALD minority parents. As shown in Table 4, the top three most-reported factors include 1) perceived home culture's attitude toward ASD (found in 10 studies, 32% of the total, to be an explicit factor), 2) parents' attitudes and understanding of ASD (found in 9 studies, 29% of the total, to be both an implicit and an explicit factor), and 3) language barriers (found in 8 studies, 26% of the total, to be an explicit factor).

In general, the results of this review indicate that the service choices made by parents for their children with ASD is a complex decision-making process influenced by various factors, including familial dynamics, characteristics of service providers, and the socio-cultural context. Although a few factors have been identified in a limited number of studies, encompassing both qualitative and quantitative approaches, there is a research gap regarding some factors that have not been thoroughly investigated, and it highlights the need for future investigations to understand better various aspects that have received less attention and their roles in the decision-making process. These include parental advocacy, the financial impact on families, the consequences of immigration status, parental concerns regarding child development, and the influence of private insurance considerations, among other factors.

5.4.2 Limitations

When evaluating these results, it is important to note the methodological limitations of the included research. In most studies, convenience sampling was used, so the result was not representative. Also, among all included studies, only seven of them were quantitative studies or included quantitative analysis, which means most of the factors disclosed in this study were self-reported or inferred from qualitative data. For example, in many studies, due to the use of online surveys in data collecting, ASD diagnoses were reported by parents instead of being confirmed by researchers.

The second limitation is that the target subjects of the included studies were not always CALD parents, and in some studies involving CALD groups, the research findings did not distinguish between the CALD groups and the entire participant pool (e.g., Bilaver & Havlicek; 2019; McLeod & DiSabatino, 2019). In addition, the classification of CALD groups in the included studies was not always consistent; for example, Khanlou and colleagues (2015) recruited 27 professionals and service providers instead of parents, and Kizildag et al. (2022) labeled 14 participants as US-born, as opposed to immigrants. However, according to the definition of CALD parents used in this study (Dune et al., 2018), being born in the US does not inherently exclude a participant from the CALD population category.

The third limitation is in the synthesis of findings. Firstly, the definition and categorization of factors were derived from previous research, predominantly qualitative research in the area of sociology. The purpose of the classification was to illustrate the results in terms of the several layers where the factors reside. However, there could be different interpretations as to where these factors should be placed, which might impact how readers understand the findings. The last limitation is that the number of studies included in the review is small (n = 31) because of the particular focus on CALD minority parents of children with ASD. Consequently, the synthesis was only able to explore in the form of a systematic review of existing literature (qualitative, quantitative, and mixed-method studies), and a quantitative or meta-analysis was not possible.

5.5 The Systematic Review and Its Relevance to the Interview Study in Study 2

Across 31 studies, 20 factors that might influence parents' decisions to the choice of were identified and the synthesis involved observing trends and providing a narrative overview of the significance of the associations between each factor and service/practice in the chapter of findings. Based on the findings of the systematic review, interview protocol and online survey were designed accordingly. The results of the systematic review and their relevance to the formation of survey questions and interview protocol are shown in Table 5 Findings of Systematic Review Included in Qualitative Instruments.

Table 5 Findings of Systematic Review Included in Qualitative Instruments

The Identified Factors	**Number (Percent) of Studies**	**If Included in the Survey**	**If Included in Interview Protocol**
Parents' attitudes about and understanding of ASD	9 (29%)	√	√
Parents' knowledge of the special education system	6 (19%)	√	√

Support from family members	3 (9%)		√
Age of children	1 (3%)	√	
Parents’ concerns about their children’s development	1 (3%)		√
Language barriers	8 (26%)		√
The way services/interventions were delivered	7 (23%)	√	√
Partnership between parents and professionals	7 (23%)		√
Out-of-pocket cost	3 (9%)		√
Waiting time for services	2 (6%)		√
Parental advocacy efforts	1 (3%)		√
Private insurance	1 (3%)		√
Perceived home cultural attitudes toward ASD	10 (32%)		√

The demographic information of parents (gender, race, educational background)	7 (23%)	√	
Social isolation	5 (16%)		√
Stigma and discrimination	4 (13%)		√
Perceived host cultural attitudes toward ASD	4 (13%)		√
Parents’ pre-existing obligations/burdens from work and life	3 (9%)		√

Chapter VI Study 2: A Qualitative Study Through Interviews and Surveys

6.1 Participants

As stated above, the subjects for this exploration are first-generation immigrant parent(s) with child(ren) diagnosed with ASD who were born either in the US or abroad. To define immigrant families, I used Singh and colleagues' (2008) description of immigrant families, which divided them into three categories: “foreign-born children with both immigrant parents (first generation), US-born children with both immigrant parents (first generation), and US-born children with one immigrant parent (first generation)" (Singh et al., 2008, p.758). Parents who were born in the US will be excluded from this study.

As suggested by Baker and Edwards (2012), determining how many participant interviews are sufficient for the current study is both a difficult practical choice as well as an epistemological appropriate question since there are no straightforward answers to the question of whether the sample size is sufficient for a qualitative study. Rather, it depends on a variety of factors, such as the amount of time needed to complete the project, the feasibility of recruitment, the satisfaction of ethics criteria, and the study's budget.

The number of participants in this study (13) reflects my pragmatic effort as a researcher to offer the diversity that is representative of immigrant parents of children with ASD from a variety of circumstances, as well as to fulfill practical needs and constraints.

6.2 Recruitment Criteria

The sample consisted of 13 participants, including 12 females and 1 male. All participants were first-generation immigrants to the United States. Among them, 7 parents were from mainland China and the rest 6 parents respectively from Hong Kong, Taiwan, Germany, Korea, Iran, and Bolivia.

According to findings of the 2020 census, 45 percent of immigrants identified their race as single-race White, 27 percent as Asian, 10 percent as Black, and 15 percent as other races (United States Census Bureau, 2020). Therefore, this study's sample does not represent the real racial composition of immigrants based on self-reported race. Despite my efforts to recruit enough participants from diverse backgrounds, the proportion of immigrant parents migrating from Asia is greater than that of parents from other racial backgrounds, and immigrant African American parents were not successfully recruited due to logistical constraints.

I recruited parent participants by three criteria: (1) parents from first-generation immigrant families in the US, (2) parents' children who have a diagnosis of ASD to ensure they have had adequate knowledge of the disability, and (3) there are no restrictions on the age range of their children since the purpose of the present study is to examine the experiences and viewpoints of parents with children spanning a wide range of ages. Table 6 and Table 7 present more details of participants' characteristics.

Table 6 Participants' Characteristics

Total number of participating parents	**13**	**Number of children described in parents' interviews**	**13**
Women	12	Girls	2
Men	1	Boys	11
Educational background of parents		Age 5-7	2
Attended college (no degree)	1	Age 8-12	6
Bachelor's degree	2	Age 13-15	2
Graduate degree	10	Age 16-18	2
		Age 19-22	1

Parents' age	
30-39	3
40-49	8
50-59	2

Marital status	
Married	11
Divorced	2

Annual household income	
0-$10,000	2
$10,000-$50,000	3
$50,000-$100,000	2
$100,000-$200,000	4
$200,000-$300,000	2

Racial background	
Hispanic	1
Asian	10
White	1
Persian	1

Employment status	
Employed, working 1-39 hours per week	8
Employed, working 40 hours per week or more	2

Services received outside school (number of times mentioned)	
Occupational therapy	2

Not employed, looking for work	1
Not employed, not looking for a job	2
Services received at school (number of times mentioned)	
Occupational therapy	8
Speech therapy	11
Applied behavior-based therapy	1
Social skill therapy	4
Physical therapy	1
Sensory integration therapy	1

Speech therapy	4
After-school program	1
Applied behavior-based therapy	5
Social skill therapy	1
Physical therapy	2
Years of Immigration	
Less than 5 years	2
4 to 10 years	3
more than 10 years	8

Table 7 Demographic Information Per Parents/Child

Parent Number	**Gender of Parent**	**Age of Parent**	**Location (State)**	**Education Level**	**Age of Child with ASD**	**Gender of Child with ASD**	**Type of School**	**Employment**
1	Female	40-49	CA	Graduate Degree	14	Male	Public School	Unemployed
2	Female	40-49	MA	Graduate Degree	10	Male	Public School	Employed
3	Female	40-49	NY	Graduate Degree	18	Male	College	Employed
4	Female	30-39	UT	Graduate Degree	8	Male	Public School	Employed
5	Female	40-49	CA	Graduate Degree	9	Male	Public School	Employed
6	Female	40-49	NJ	Bachelor's degree	7	Male	Public School	Employed

7	Female	40-49	TN	Graduate Degree	17	Female	Public School	Unemployed
8	Female	40-49	MI	Graduate Degree	9	Male	Public School	Employed
9	Female	40-49	CA	College	9	Male	Public School	Unemployed
10	Female	30-39	CA	Bachelor's Degree	9	Male	Public School	Employed
11	Female	30-39	NY	Graduate Degree	7	Male	Public School	Employed
12	Female	50-59	SC	Graduate Degree	15	Female	Special School	Employed
13	Male	50-59	NY	Graduate Degree	22	Male	n/a	Employed

6.3 Recruitment Procedure

Recruitment for this study was carried out in two methods. Since this is a study focusing on immigrant parents' experiences, parent participants were selected by using a mixture of purposeful sampling (Patton, 2005) and snowballing (Goodman,1961). Snowballing is a recruiting strategy that allows existing participants to recruit individuals they know who are already enrolled in the research, and those new participants, in turn, recruit people they know who are already enrolled in the study (Lakhanpaul et al., 2020; Goodman, 1961). Purposeful sampling is a technique widely used in qualitative research to identify and choose information-rich cases for the most effective use of limited resources (Patton, 2005). The sampling involves identifying and selecting individuals or groups of exceptionally knowledgeable or experienced individuals with a phenomenon of interest. In addition to knowledge and experience, Spradley (1979) noted the importance of availability and willingness to participate and the ability to communicate experiences and opinions in an articulate, expressive, and reflective manner (Spradley, 1979).

Immigrant parents of children with ASD were recruited using social media platforms such as Facebook, Weixin (the most popular instant messaging app for Mandarin speakers), and Twitter. To obtain a sufficient number of participants from a diverse range of backgrounds, I first attempted to contact at least one person from each background and then utilized snowballing to recruit more people from the same background. Among 13 participants, 4 of them were recruited through purposeful sampling by me and the rest 9 participants were recruited through snowballing.

As a parent of a 13-year-old boy with ASD, I am an active member in several online and offline parent organizations, the majority of which are closed private groups by invitation whose members must be parents of children with special needs, including ASD, Down Syndrome, ADHD, etc. Some of the parent groups are further classified based on the types or levels of disabilities of children. For instance, parents of children with mild to moderate ASD may join the same subgroup and parents of children with mild to severe ASD may join another group. The way in which parents are spontaneously organized according to the types of disabilities echoes with the findings of a few studies on parent intervention, which found that parents whose children have similar the same types of disabilities will establish a unique relationship with more understanding of each other, thus increasing the outcomes of parent's intervention programs (e.g., Sanni et al., 2015).

In these parent groups, parents remain anonymous to one another, and participants are not asked to provide any personal information. Even though parents may use these groups as safe places to vent their frustrations, ask for assistance, or simply share stories about their lives and the experiences they have had with their children, their personal information will not be known to other group members unless they identify themselves to the group.

I began my research by disseminating a recruiting flyer over several social media platforms, including Facebook, Weixin (the most popular instant messaging service for those who understand Mandarin), and Twitter (**Attachment 2 Recruitment Flyer**). I also got in touch with a few parents from these parent groups who were already familiar to me. They assisted me in disseminating the information on the study as well as the recruitment flyer to a greater number of prospective participants by publishing it on a greater number of platforms and public or private parent groups or ASD-related organizations.

Parents interested in taking part in the study contacted me and I scheduled interviews with each of them and sent out two links, one is the consent form (**Attachment 3 Consent form**) as required by the human subject committee, and the other one is a link to the on-line survey (**Attachment 4 Survey**) on Qualtrics so they could fill it out before we conducted the interview. Due to the constraints during the Covid-19 pandemic that people were keeping social distance and having health concerns, these interviews were conducted online through either Zoom or by phone.

All participants (13) were given a thorough explanation of the research as outlined on the permission form. After obtaining permission, I performed the interviews. Parents were advised they might change their minds at any point during the interview and withdraw from the study without repercussions. Three individuals shed tears when discussing their experiences and responses when their children were first diagnosed with ASD. No participant showed any outward symptoms of discomfort throughout the interview, and no participant expressed a desire to withdraw from the research. No individuals were compensated or otherwise rewarded for their participation in this research.

6.4 Consent

Using the standard format, the consent form was developed in accordance with the standards established by the University of California, Santa Barbara's human subject committee. Before the interview, participants were asked to sign a consent form using an online signing app such as DocuSign, and all documents were securely stored on a hard drive encrypted specifically for the research.

Each time, an interview was conducted with only one of the participants. During the course of my interviews with each participant, I took precautions to ensure that all links and documents were distributed using the correct email address and names of recipients. This was done to prevent any of the participants' personally identifiable information from becoming public due to errors that may have occurred during the process. I also made certain that every possible participant I met with had the capacity to comprehend the knowledge that was presented to them.

6.5 Instruments

6.5.1 Survey

The survey consisted of 14 questions, comprising 10 structured and 4 unstructured questions, to gather information on participants and their children to address the study's research questions. The 14-question online survey is divided into two sections: the first section contains demographic and ASD-related service information regarding participants' children with ASD; the second section contains demographic and immigration-related information about participants.

The survey questions were prepared based on this study's research questions, the result of a systematic review, and adapted from previous studies regarding the perspectives of parents of children with ASD on services (e.g., Carter et al., 2011; Akins et al., 2014). The survey was designed to be completed within 10 minutes without any self-assessment questions. The decision was made according to the findings of previous studies that sometimes too many questions in a survey will decrease the participants' compliance and interest to participate in the study. According to studies, surveys should aim to remain between one to three minutes (Kimhy et al., 2012; Raugh et al., 2019).

Also, the order of survey questions was considered. There is a variety of studies on question order in the literature of psychology and survey research which investigates whether questions, or the replies to the questions, are impacted by questions that came before them. These studies suggested that it is possible that an answer to a question was prompted by the substance of the question itself, but it's also possible that the response was prompted by the sequence in which the questions were asked and the choice that was taken to place the questions in that order. (Carter & Prevost, 2017). Due to the absence of short-answer questions in the survey and the fact that all questions pertain to factual information about demographics and their choices of services, the findings about the structure and functions of a survey do not apply in the present study. In this study, the order of questions in the survey was arranged from children's information to participants' information.

6.5.2 Interview

Individuals semi-structured were chosen as the preferred method of data collection to allow participants time to discuss the topic area confidentially and openly in depth without being influenced by the perceptions of other participants. Semi-structured interviews were conducted with participants lasting between 45 to 90 minutes with an average interview length of interview being 54 minutes. Interviews were audio recorded on two devices to ensure that data would not be lost. Interviews were conducted in both Mandarin and English at the choice of participants. Interviews were transcribed and anonymized, and all data was stored in accordance with IRB requirements.

The interviews were conducted based on a semi-structured interview protocol (**Attachment 5 Interview Protocol**) developed based on the findings of the systematic review, as well as the suggestions that ideally interview protocol is supposed to be developed based on "how" and "why" questions and was reviewed by a party of interest who was familiar with the topic (Willis, 2006; Kaiser et al., 2020). In the process of developing the protocol, I invited another parent of a child with ASD (who was not the subject of this research) and my advisor, Professor Diana Arya, to review the drafts, and they provided me with valuable feedback that allowed me to ascertain comprehension of the embedded question and response processes. For instance, parents were asked to respond to obscure or theory-based questions, such as "what your vision for an ideal inclusive education system is;" nevertheless, I attempted to employ a series of sub-questions to represent how parents arrived at their responses. I also used various qualitative research strategies, such as restating stories in their own words, clarifying the meanings of the expressions, and expressing if the question truly represented respondents' experiences (Kaiser et al., 2020).

Throughout all the interviews, I remained cognizant of the fact that parents may be exhausted during the interview and that they may be under time constraints because some of them are full-time caregivers of their severely autistic children, which requires them to attend to their children on occasion. I attempted to provide as much flexibility as possible during these interviews and to avoid disrupting their everyday lives unnecessarily.

Also, as I said in the section ‘researchers' positioning,' I was conscious of the possibility that I may skip questions because I believed I already knew the answers, which is a significant disadvantage as both an insider and researcher (Breen, 2007). To counter this bias, I kept an open and inquisitive attitude while requesting further information. Questions such as "Could you please elaborate?" and "What comes to mind when you say that?" are open-ended. Or, "Could you maybe provide an illustration of what you just said?" were questioned even though the scenario they described resonated with what I experienced as an immigrant parent of a kid with ASD in the United States. These strategies have been effective in prompting and encouraging participants to adopt a more "expert" attitude and speak more freely about their experiences and viewpoints.

After I had finished each interview, I would sit down and write a detailed reflective piece that included any ideas, thoughts, or observations that stood out to me. By maintaining these records, I attempted to document how I interpreted the interview data so that I could preserve a record and go back to it at a later time. A disadvantage of the research is that I was unable to observe any non-verbal cues or physical gestures that were used to punctuate or explain a point participants might want to make since all the interviews were done remotely.

6.6 Ethical Considerations

In December 2021, the University of California, Santa Barbara Human Subjects Committee authorized this project (protocol number 7-211-0754). The systematic review protocol was registered on INPLASY, which is an international platform for review and registry services of meta-analysis studies and systematic review. Throughout this research, ethical considerations were made to ensure that the study complied with the core principles of human research ethics as outlined by the committee. As outlined, the researcher's responsibility includes ensuring that the human subjects are treated with dignity and respect and suffer no more than minimal harm because of the research (Shea, 2000); throughout the whole process of my study, I have maintained a steadfast adherence to these criteria.

Also, from a personal perspective, it's important to be aware of which questions are asked and which ones are not asked in the interview and poll because immigrant parents may have had traumatic experiences raising their children with ASD. For questions that would probably bring up these traumatic memories, like "What is the worst experience of service you had for your children in the past?" I changed the question to something like, "Could you please share with me something that impressed you the most about the service?"

6.7 Analytic Process

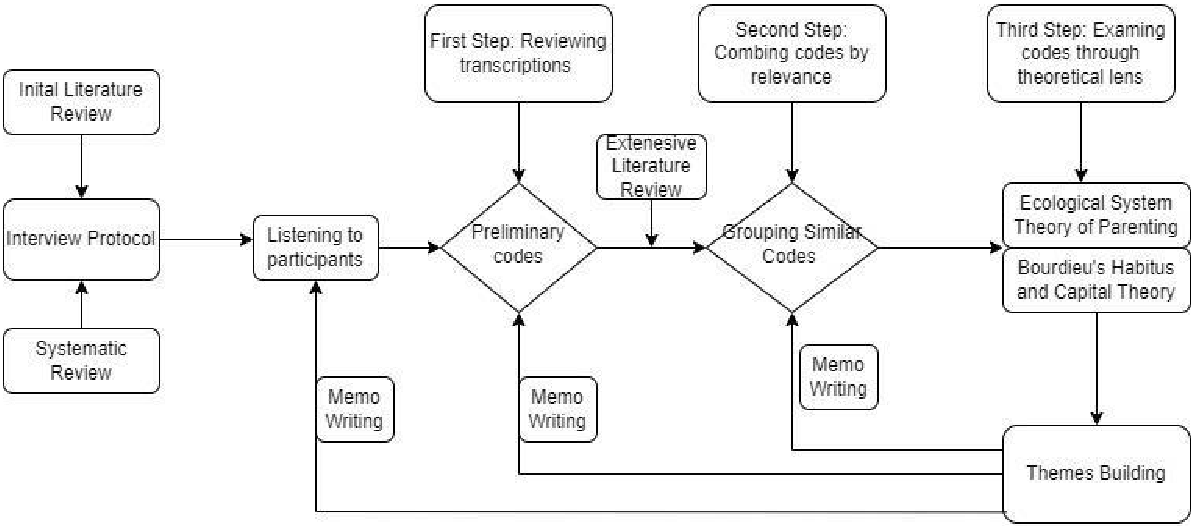
6.7.1 Initial and Extensive Literature Review

There are two kinds of literature reviews: narrative or conventional literature reviews and systematic reviews (Cronin et al., 2008). The narrative literature review was described by researchers as the process of condensing the literature based on certain criteria for the selection of sources (Silva et al., 2019). An extensive literature review, on the other hand, establishes explicit and organized criteria for the search and analysis of material on the topic under investigation. The extensive review of the literature, according to Denyer and Tranfield (2009), will provide more rigor, robustness, and reproducibility to research. In the current study, both literature review approaches were selected to offer a comprehensive perspective of the literature and their results pertinent to the research objectives and questions.

For qualitative researchers, the use of literature is a controversial topic. According to Bryant and Charmaz (2007), it is essential for researchers to access and use the current literature pertinent to their investigations. Holton (2008), on the other hand, took a purist stance and argued that to develop a theory based on qualitative data, researchers should not begin by conducting an extensive review of the literature because it would limit theory development because researchers would be exposed to preconceived notions before forming their own. Bearman and colleagues (2012), qualitative researchers, proposed that as the opinions and perspectives of researchers vary over time, researchers must explain and justify their decision about the timeliness of their literature review and how they would utilize current information. In addition to emphasizing the significance of judgments on the time range of literature, they noted that one of the most significant rules for doing a literature review is to not depend just on the study hypothesis to assure the review's completeness. In conclusion, there are controversies about the ways and timing of conducting a literature review, and most researchers have proposed that a literature review must be undertaken using a complete, systematic, and transparent technique of finding and analyzing literature to discover the key findings and themes arising from the literature.

Therefore, while performing the literature evaluation for this research, I employed a combination of traditional literature review and qualitative extensive review. A preliminary literature review was conducted to clarify the significance of the research and provide a persuasive argument for the research proposal. Then, I conducted a systematic review based on a combination of search terms on a major database. After that, an extensive literature review was carried out after the initial open coding. Delaying an extensive literature study served the objective of preventing the imposition of pre-set assumptions onto the analysis and allowing me to express my own thoughts free from the constraints of previously established theories (Holton, 2008). During the process, memo writing was used to record emergent ideas and insights as well as to indicate occasions when thoughts of the data's relationship to existing literature were stimulated. The analytic process was presented earlier under section 4.1, and I present it here again for a recall as below in Figure 2: Analytic Flowchart

Figure 2 Analytic Flowchart



6.7.2 Initial Open Coding of Qualitative Data

Initial coding was performed in accordance with suggestions by constructivists such as Charmaz (2014), who recommend that researchers stay close to the data by employing action-oriented coding and keeping codes brief and accurate. Under this method, researchers can define what is occurring in each line and prevent them from creating loose descriptive codes that lose the significance of the data. During the process of initial coding, I listened to the audio recording of each participant's interview to identify the participants' emphasis, clarify my comprehension, and verify the correctness of the transcription. An example of line-by-line initial coding can be found in Table 8 Examples of Initial Coding as below.

Table 8 Examples of Initial Coding

Participant's Quotes	**Initial Open Coding**
'I don't know how long I could handle it on	Feeling of lost

my own and it made me anxious from time to time'	Experiencing mental stress
My parents are still in China and if anything comes up now, I could not come back'	Being away from family support
And I wish I have a relative around so that I could have some help…	Needs family support

6.7.3 Memo Writing of the Emerging 'Phenomenon'

Throughout the study, I wrote case-based memos and conceptual memos. According to Sbaraini and colleagues (2012), in a qualitative study, there are two types of memos written in the process of analysis and coding: case-based and conceptual memos. Case-based memos were written after each interview, which aimed at containing the interviewer's impressions about the contents of the interviews, including participants' expressions. Conceptual memos, on the other hand, were a form of making sense of initial codes and understanding processes, including when they occurred and changed and what their consequences were. According to Charmaz (2014), memos help the evolution of ideas and give a platform for critical reflexivity among researchers. In this study, I employed both case-based and conceptual memos.

After each interview, I wrote a case-based note in which I reflected on what I had learned, focusing on my views of the participants' experiences and the interviewer's responses. I also jotted down my views on pre-existing concepts and their connections to what was spoken in the conversation. **Table 9** displays a case-based memo example. After a few interviews, the interviewer/researcher began comparing and noting differences between these notes. As reported by Charmaz (2014), I also developed conceptual memos regarding the development of the initial and focused codes.

According to Charmaz (2014), while keeping conceptual memos during research, researchers are suggested to ask the following questions to maintain a focus on research questions and directions:

- *What process is at issue here? How would you define it? To what extent is it explicit or does it remain implicit?*
- *Under which conditions does this process develop?*
- *How do the research participants think, feel and act while involved in this process?*
- *what slows, impedes, or accelerates the process?*
- *When, why and how, and under what conditions does the process change?*
- *What are the consequences of the process?* (Charmaz 2014, p. 169)

I employed conceptual memos to document my thoughts on the significance of codes and how, when, and why processes happened, shifted, and had repercussions. In these memos, I compared data, instances, and codes to identify parallels and differences, and I posed questions that would be addressed in subsequent interviews. **Table 10** illustrates a conceptual memo.

Memo writing is helpful for me to focus on the interpretation of the phenomenon emerging from the interviews instead of making conceptual jumps based on pre-conceived assumptions. Specifically, memos were useful in elucidating links and comparisons within the data, which brought depth to the process of conducting research. Memos made it possible for me to record my ideas and assumptions as soon as they occurred. This procedure assisted me in refocusing my attention on the data, which made it much simpler for me to stay as connected to and rooted in the facts as possible.

Table 9 An Example of Case-Based Memo Writing

Memo Jan 2nd, 2022- with Participant 5

This is an emotional interview and the interviewee cried in the middle of talking about how she lost one of the twins and how hard it was for her whole family to take care of a pre-term baby back then. The participant was direct and open about her experience when navigating the special education system at school as well as services provided by companies.

Therefore, my question is, what is your experience in navigating the special education service in the United States, and is there a particular reason why you chose services? I found that the participant's kid was referred to a private clinic, and according to the participant, she stopped visiting after a few sessions because she felt uncomfortable returning. I asked her more about the way she felt uncomfortable, and she stated that she believed the therapist was in a rush to ask them to go, even though there were still around five minutes remaining, and that she felt unwelcome.

Although unrelated to my research question, when the participant described services she did love, she talked about her experiences after losing one of her twins at the hospital. She mentioned how helpful it was when she joined a parents’ group organized by the

hospital where the parents losing their children could share their experiences with each other and support each other. On the other hand, the participant talked about her experiences with school, she said sometimes there were misunderstandings as she described ‘might be the case due to miscommunication’, for example, she said she informed the school that her son has a eating disorder and a severe allergy to dust, she also provided pills and prescriptions from doctors to the school nurse, however, she said she still got calls from school asking her about his son’s situation, which made her doubting if the school really took notes of what she reported before.

Table 10 An Example of Conceptual Memo

Old concepts+ new concepts = stress, miscommunication, and self-reflection **Jan 5th 2022**
In the previous interview, participants talked about their experiences when they moved to a new country and the challenges they faced when navigating the special education system in the United States. A few of them talked about their IEP meeting experiences and how it went unsmooth because of language barriers. According to the parents, they made efforts to embrace the ‘new school culture’ here by ‘learning what other parents would do’; however, they felt sometimes their efforts did not work well. One parent talked about how it was confusing for her to tell the difference between ‘this misunderstanding arises because I am not familiar with this culture’ and ‘it is because I did something wrong and upset others’, and it burdened her because she thought it is not right to bother others.

Embracing new concepts/paradigms/systems and abandoning old ones was quite evident during this process (old concepts = teacher/school-oriented model; new concepts = student/parent-oriented model). This evolving process involved feelings such as anxiety, doubt, indetermination, lack of confidence, and shamefulness. The transition happened when parents felt that perhaps there was something else that would be worth doing; something that might be a little different from what they were familiar with in their home country when they advocated for their children with special needs. The sense of responsibility of parents to offer the best available service/treatment for their children might have triggered this transition as well. However, there are other factors that play an important role during this process such as parents' personal features, preconceived notions, living environment, and how parents combine their children' needs and their expectations while making service decisions. Furthermore, finding the balance between accommodation-based services (social constructive paradigm?) and intervention-based services (curing of disease paradigm?) is a challenge for parents to decide on, and some parent said they had disputes with their spouses about how to choose among different service because they held very different perspectives toward ASD. Parents also talked about learning and adapting new concepts in this process, and many said they would never be going back the way it was before in their home culture.

6.7.4 Focused Coding

Focused coding is the second major step of analysis, in which codes that emerged more frequently during initial coding and those that are more relevant to addressing the research questions are synthesized together as emerging themes. The initial coding entailed zooming in on the data at a micro level, whereas focused coding included zooming out and observing the bigger picture through larger data segments. The process of focused coding assisted in highlighting emergent notions and interpretative ideas without sacrificing the detail collected during the initial coding procedure. In the meantime, I moved back and forth between the identification of similarities and differences within categories as suggested by Willig (2013), to ensure the construction of themes remained speculative, requiring testing by continuous comparison analysis.

Focused coding proceeded until the development of hypothetical categories, which led to the development of significant categories and, ultimately, the emergence of the core category. Table 11 provides an example of focused coding in which the development from raw transcript to focused themes was recorded.

Table 11 An Example of Theme Building Process

Themes	**Codes**	**Sub-category**	**Examples of excerpts**

Mental stress arising from being away from family support network	Anxiety	Anxiety for self	‘I don’t know how long I could handle it on my own and it made me anxious from time to time’
		Anxiety for others	‘My parents are still in China and if anything comes up now, I could not come back’
	Loss	Loss of support from family	‘I wish I have a relative around so that I could have some help…’
	Worry	Worries for self	‘I am worried that I will have to quit my job eventually if my parents could not come over to help me’
		Worries for their children	‘I hope I have a relative around that I could arrange a playdate for him coz it is difficult to do it with others, you know, people are afraid of get contracted by virus’
Mental stress because of the communication shift from in-person to online	Frustration	Frustration occurred in communication	‘And online meetings make everything much more difficult; I mean…feel like you're talking to your computer.’
		Frustration in advocacy	‘You can image how frustrated we were when you tried to advocate for their right, but the network suddenly got spotty, and the conversation was interrupted.’
	Confusion	Confusion occurred in communication.	‘You know how sometimes you can't find the right word to communicate your feelings in a zoom meeting’.
		Confusion occurred in understanding rules	‘You stammered and had to say something to fill the silence, and you said something that isn't exactly what you meant to say and made everyone confused’

Mental stress due to insufficient staffing and frequent changes of routine.	Overwhelmed	Too much parenting workload Lack of support from practitioners	‘I honestly don't know how other parents it did when they had to work at home and care for autistic children at the same time... It's been quite stressful... I cook for him and his sister, and I have to keep an eye on him when he's playing and teach him his assignments when paraprofessionals or therapists are unable to be at our place’
	Changes in routine	High turnover of practitioners	‘We have had 6 different occupational therapists working with us since COVID-19, and none of them worked long time with my son, so we have to make adjustments often according to their availabilities.’

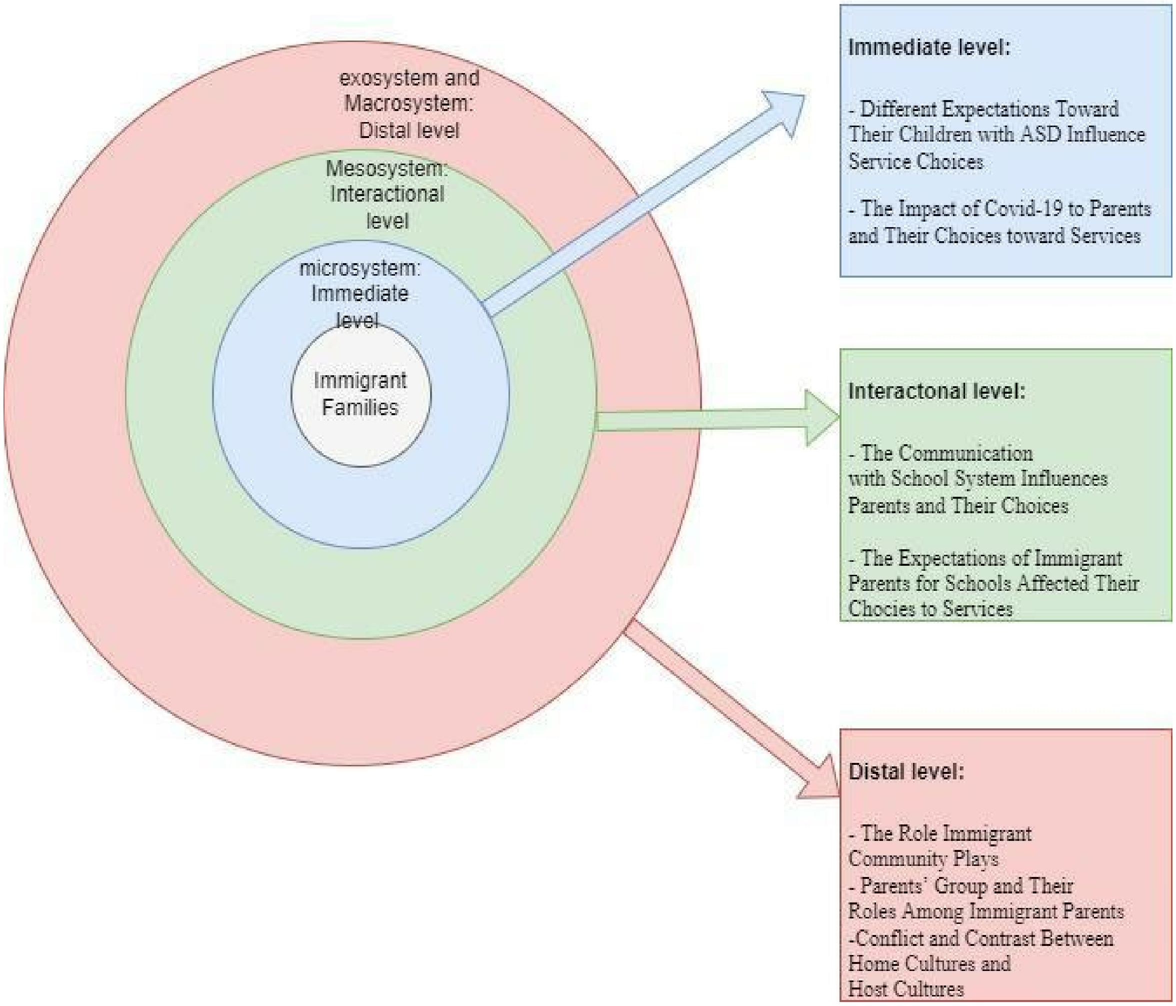
6.8 Findings of Study 2

6.8.1 Overview of Findings

Consistent with the presentation of findings of study 1, the findings of study 2 are presented as they occur across the ecological system, including at the immediate (micro-systemic), interactional (mesosystemic), and distal (exo- and macrosystemic) levels as well. The findings are illustrated with extracts from participants’ narratives, which are italicized in places with quotation marks. It was not feasible to offer a complete picture of all the categories and topics contained in the study due to the broad scope of the data. While examining and coding the data, I asked myself the following questions in the process of theme formation and these questions include but are not limited to: (1) How does an immigrant parent get access to services for their children? (2) what matters in immigrant parents’ decisions to services? (3) what does ‘good service’ look like from immigrants’ perspectives? (4) what helps make ‘good service’ Possible? (5) what are the outcomes of services provided by different providers? and (6) What is the goal of services from immigrant parents’ perspectives?

According to the findings, immigrant parents' choice of services for their children with ASD is a complex process, and their notion of a good service is a result of a multi-layered, highly personal experience. All participants described their process of navigating the special education system in the United States, and there was a shared sense that the choice of service was more than an examination or comparison of the service provided, it was a social process that involves the exchange and interaction between and within players and structure, such as parents, practitioners of special education, and communities. Also, it was more about how immigrant parents adapted their original beliefs about ASD as well as corresponding services and made an effort to fit into the perceived understandings and assumptions about the values embedded in societies in the United States about equity, disabilities, and so on. Figure 4 shows the main categories of findings as they occur across the ecological system; table 12-Major Themes and Sub-themes and Table 13-Themes and Coding Summary provides an overview of key themes and codes generated as instructed by qualitative researchers such as Glaser (1992).

Figure 4 Preliminary Findings in Context of Ecological System



Immediate level:

- Different Expectations Toward Their Children with ASD Influence Service Choices
- The Impact of Covid-19 to Parents and Their Choices toward Services

Interactonal level:

- The Communication with School System Influences Parents and Their Choices
- The Expectations of Immigrant Parents for Schools Affected Their Chocies to Services

Distal level:

- The Role Immigrant Community Plays
- Parents' Group and Their Roles Among Immigrant Parents
-Conflict and Contrast Between Home Cultures and Host Cultures

Table 12 Major Themes and Sub-themes

Category Themes	**Immediate Level(a)**	**Interactional Level(b)**	**Distal Level(c)**
Major Themes	Parental service choices are related to their expectations of their children.	The selection of services by parents is influenced by their communication with schools.	The role of the immigrant community played in their choices/rating to service.
		The selection of services by parents is influenced by their communication with specialists.	The role of parents' group played in their choices/rating of service.
	Covid-19 and its impact on parents' service choices	The expectations for schools and their relationship to	Perceived home culture and

		parental selection/ratings of services.	host culture perspectives on disability/ASD and parental service selection.
Sub-themes	1. Academic performance-focused parents and their selection of "aggressive" services. 2. Parents' perception of ASD as a phase and their decisions to services. 3. Parents who merely desire for their children to have a pleasant life and their choices to resources.	1. The move from in-person to online communication led to miscommunication between parents and schools and impacted parents’ rating to school-based services. 2. The attitudes of schoolteachers played a significant role in parents' selection/rating of services. 3. Options about behavior-based services and contacts with professionals.	1. Experiences with ethnicity-based immigrant communities in terms of service resources. 2. Help and assistance parents got from parents’ in-

	4. Parents who anticipated their children to attain academic success and the services they choose. 5. Covid-19-related societal restrictions and their effects on parental service selection. 6. Short staffing during COVID-19 and service options for parents.	4. Options for alternative services and exchanges with specialists. 5. Different parental expectations exist for school-based programs and services. 6. The parental occupation and their selection of services.	person and on-line groups. 3. Similar experiences strengths bonding among parents. 4. Perceived home cultural perspectives toward disability and ASD. 5. Perceived host cultural attitudes toward disability and ASD.

Table 13 Themes and Coding Summary

No. of Sub-themes as listed in Table 12	**Category in Ecological system**	**Properties of (as in Bourdieu's social interaction theories)**	**Dimensions (Glaser, 1992)**
(a) 1	Immediate Level	Habitus	Action/interaction strategies
(a) 2	Immediate Level	Habitus, Cultural Capital	Action/interaction strategies
(a) 3	Immediate Level	Habitus	Action/interaction strategies
(a) 4	Immediate Level	Habitus	Action/interaction strategies
(a) 5	Immediate Level	Social capital	Intervening conditions
(a) 6	Immediate Level	Social capital	Intervening conditions
(b) 1	Interactional Level	Social capital	Phenomenon and Context
(b) 2	Interactional Level	Social capital	Action/interaction strategies

(b)3	Interactional Level	Habitus, cultural capital	Action/interaction strategies
(b)4	Interactional Level	Habitus, cultural capital	Action/interaction strategies
(b)5	Interactional Level	Social capital	context
(b)6	Interactional Level	Social capital, cultural capital	context
(c) 1	Distal Level	Social capital	Action/interaction strategies
(c) 2	Distal Level	Social capital	Action/interaction strategies
(c) 3	Distal Level	Social capital, cultural capital	Context
(c) 4	Distal Level	Cultural capital, habitus	Consequences
(c) 5	Distal Level	Cultural capital, habitus	Context

6.8.2 Within the Immediate Micro System of Immigrant Families

Immigrant parents' immediate system refers to the persons or groups that have the most immediate and direct influence on the family, such as the schools their children with ASD attend or their classmates at school or in the community with whom they mingle and interact daily. This category includes family members, including parents, grandparents, relatives, and children. Parents' narratives revealed that individuals who had direct and immediate contact with their family life, their situations, ideas, and viewpoints about ASD play a significant influence in service decision-making.

Different Expectations Toward Their Children with ASD Among Influence Service Choices

When talking about service choices for their children with ASD, parental expectations and the resulting variations in service options emerged as a recurring subject. In this context, expectations include those regarding the child's professional path, the outcome of the intervention, and variances in expectations regarding the significance of academic accomplishment.

When asked about the experience of raising children with ASD and the process of selecting services fit for them, all 13 immigrant parents talked about how their expectations toward their children with ASD in terms of their career path differ and various expectations have led to their different choices of services.

'*…We just want him to be happy, so we don't want to put too much pressure on him... We tried ABA before and believed it did not work well for him because they pushed him too* *hard, and we do not believe it is necessary…' (Parent 12, mother of a 16-year-old girl with ASD)*

'*…We want him to be successful in the future, to be able to fit into society and have his own career. We believe he can achieve this objective, and we have located a therapist who can assist him with arithmetic and writing.…' (Parent 11, mother of a 7-year-old boy with ASD)*

Immigrant parents implied that they had distinct expectations for their children with ASD. Furthermore, different expectations influenced their selection of services for their children. For example, among all 13 participants, parent 1, parent 12 and parent 13 expected their child to lead a happy life in the future so they did not prefer interventions which are more 'aggressive' than other assisting methods. When compared to the above-mentioned 3 parents who mentioned that they want their children with ASD to have a happy future, the rest 10 parents who implied that they want their children with ASD to have a successful profession are more likely to choose services over academic help for their children with ASD.

Furthermore, when discussing their choices of services, parents discussed their beliefs regarding the possible results of services and interventions. It appears that different expectations toward the results have led to varied choices of services, as they were the topic of discussion when parents were discussing their preferences.

For instance, parents who have indicated that they feel ASD symptoms are temporary and that they would disappear because of the progression of treatments are more likely to select more "aggressive" services, which focus on minimizing troublesome behaviors.

‘…*I had no idea how bad ASD could become at the time, and I am the type of person who never gives up and believes there is nothing in this world that I cannot accomplish... So, I spent the majority of my time back then working with him with a BCBA therapist, and I asked my department to reduce my course burden so that I could devote all of my efforts to him...*’ (Parent 2, mother of a 10-year-old boy with ASD)

However, when parent 1 realized later that ASD might be a series of life-long traits that won’t go away as her son grows, she indicated that her attitude toward services changed.

‘…*I will discuss ABA with you later because I believe it is problematic... He's not making as much progress as I thought, so I've signed him up for some online art classes, you know because everything has gone online since the Covid...*’ (Parent 2, mother of a 10-year-old boy with ASD).

Parents are subject to the influence of their family members as well as their expectations when it comes to the process of selecting services for their children with ASD.

‘…*My mother does not believe ASD is something that has to be addressed or dealt with, so we did not consider seeking services at first; moreover, Covid was just starting at the time, so we basically just sat at home and did nothing….*’ (Parent 8, mother of a 9-year-old boy with ASD)

‘…*His father struggled to recognize that his kid has ASD, and we battled a lot over it. It bothered me because he seemed to believe that my parenting style was to blame and that there was no need to seek professional aid for such a family issue….*’ (Parent 9, mother of a 9-year-old boy with ASD)

Although the expectations and opinions of family members may at times have prevented parents from seeking services, some of those parents also noted that the expertise of their family members may have contributed to the early detection of ASD and the understanding of how important it is to seek services.

'*…I knew nothing about ASD at the time, and I assumed it was just a normal developmental process because he was so young. However, my husband is a doctor, and he thought we should take him to a specialist because he believes he may have autism because a typical child of his age should have been talking by that time…*' (Parent 10, mother of a 9-year-old with ASD).

It is also obvious from the narratives of parents that the perspectives or expectations of family members can impact not only whether the appropriate assistance is required for their children who have ASD, but also the particular kind of service choice that is influenced by their perspectives.

'*…I do not believe in ABA because I think they are too pushy to my son, and it feels like they are treated like machines instead of human beings…* '(Parent 1, a mother of a 14-year-old boy with ASD)

'*…I tried floor time since we were sent to them, and I had heard from friends that it did not work for other children, so we stopped coming thereafter that…*' (Parent 9, mother of a 9-year-old boy with ASD)

It seems that parents' preferences differ according to their expectations and beliefs about the focus of intervention or services: Should it be social-oriented or academic-oriented and the variations in the answers to this question may have led to different choices of services among parents.

'*…I believe that social skills are the most crucial for children like him since they lay the groundwork for him to be able to live in the world… He is currently receiving ABA from one of the best therapists we have ever worked with, and he has made tremendous development in social skills…*' (Parent 9, mother of a 9-year-old boy with ASD)

'*…After he grows up, how will he make a livelihood without an official diploma? I enrolled him in reading and math classes, and he is doing well in them. I also intend to relocate to a better school district so that he may receive a better education...*' (Parent 11, a mother of a 7-year-old with ASD)

In conclusion, the different expectations that parents and their close family members have of their child with ASD, including service prospects, the core and definition of ASD, future career prospects, and the different expectations and perceptions of the focus of the service or intervention itself, all work together to influence the decision that parents make regarding whether or not they will choose services or interventions for their child, as well as the type of services that they will choose.

The Impact of Covid-19 on Parents and Their Choices toward Services

When discussing their experiences picking services for their children, immigrant parents also discussed the influence of COVID-19 on both their parenting and service selection experiences. According to parents' accounts, social constraints, suspension of services, and discontinuance of socializing that took place during the Covid-19 pandemic have produced conflicts among their family members, increased parental obligations, and aggravated symptoms linked with ASD. This was especially obvious in the case of the younger children. For some who are now adults or teens, social isolation during the pandemic had limited influences on them, according to their parents.

1) Impact on Social Lives of Children with ASD and Their Families

8 out of 13 immigrant parents reported that they have not seen other family members (including spouses, parents, grandparents, and relatives) residing in other countries since the worldwide outbreak of COVID-19 in 2020 due to travel bans and restrictions. During interviews, when asked about their experience during the pandemic, parents reported the insecurity and isolation because of the COVID-19-related restrictions and the mental stress as a result of staying away from family support.

'…we don't have family members to support us, like grandparents, you know, because of COVID, they could not fly over, so it is all on me…" (Parent 8, mother of a 9-year-old boy with ASD)

'*…it is not that we chose to be stressed out…we simply don't get help from family members, for example, pick him up from therapy when we are both at work…*" (Parent 9, mother of a 9-year-old boy with ASD)

Additionally, parents expressed their insecurity and loneliness as a result of COVID-19 social restrictions, which they must balance with their desire to provide social interactions for their children with ASD, whose social communication deficit is widely regarded as one of two core manifestations (along with restricted and competitive behavior) for diagnosis criteria (Lord et al., 2000).

‘…*It hurts to see his social skills decrease so drastically during COVID, and there is nothing we can do because we have no relatives here and it is difficult to arrange any kind of play date for him…*’ (Parent 8, mother of a 9-year-old boy with ASD)

‘…*I'm worried and exhausted all at the same time... I feel like I need more alone time, and I also need to play with him more because I am the only one, he can play with at home, and everything is closed now, I wish we had a relative around whom he could play with…*’ (Parent 5, mother of an 9-year-old boy with ASD)

However, two parents with children ages 18 to 22 claimed that the stay-at-home order is even preferable for their children with ASD because they are not socially engaged and being at home is rather fitting for their personality.

‘…*My son is relieved that he can stay at home, and he has no issue maintaining a social distance from others because that is his thing: avoiding people. His younger sister, who is socially active, couldn't stand it and grieved when she couldn't hang out with friends, but my son is completely OK with it.*’ (Parent 13, father of a 22-year-old son with ASD)

‘…*The COVID thing doesn't seem to bother her at all, and she'll simply do her thing while I'm working at home. I cook for her and that's about it, and I'm relieved because I don't have to drive her to school…*” (Parent 12, mother of a 15-year-old girl with ASD)

The fact that both parents have children who are of legal age to work, and one of them is already employed, should be mentioned. In comparison to the attitudes of parents of younger children, their attitudes are substantially more relaxed and less stressful.

According to the findings, parents of young children with ASD are experiencing mental stress because of being away from family support, and they are finding it difficult to balance the need to maintain social distance with the need to provide intervention-oriented social service arrangements for their children when family support is not available.

2) Increasing Parenting Stress Due to Staffing Shortage of Service-providers

According to previous research on parenting issues during the COVID-19 pandemic, parents of school-aged children are experiencing changes in their everyday lives, such as increased parenting time, but are also experiencing higher levels of fear, despair, and stress because of those changes (e.g., Davenport et al., 2020; Cameron et al., 2020). The findings of this study echo these statements, as most parents (10 out of 13) reported that they have to spend more time on parenting, not only as caregivers but also as intervention providers during the pandemic because of staff shortages of practitioners in special education.

'*...I honestly don't know how other parents did when they had to work at home and care for autistic children at the same time... It's been quite stressful... I cook for him and his sister, and I must keep an eye on him when he's playing and teach him his assignments when paraprofessionals or therapists are unable to be at our place... I experienced a panic attack not long ago and was terrified, and I am now on antidepressant medication…'* (Parent 5, mother of a 9-year-old boy with ASD)

*'...I sometimes feel helpless and cry a lot, and I'm not sure what will happen to him in the future if this continues... I feel like there is so much I need to do right now and so little I can do.…" (*Parent 9, mother of an 9-year-old boy with ASD*)*

Parent 9, the mother of a 9-year-old boy, was at home for quarantine with her son, who tested positive for COVID-19 at the time of the interview, and her comments indicated that under COVID-related restrictions it is even more difficult for parents to manage and balance their roles as primary caregivers and intervention providers when professional support is no longer available.

Other parents expressed similar concerns and anxieties about the COVID-related restrictions, which resulted in the inaccessibility of specialists critical to their children's intervention, and how the tension was alleviated once these services were restored.

‘*...he was doing quite well before the pandemic; but, once the pandemic began, I saw his social and academic step back so badly staying at home, and I was also under a lot of pressure, so I paid for an outside behavior therapist to come home to accompany him...it is out of pocket, but I feel much relieved from all these stress…’* (Parent 8, mother of a 9-year-old boy with ASD)

Additionally, it is noteworthy that due to adjustments to attendance policies, as a result of staffing shortages in public schools (including schoolteachers and nurses) as well as safety concerns because of COVID-19, parents of children with ASD are more likely to be contacted by schools to pick up their children due to physical or behavioral issues at school, such as eating disorders or tantrum throwing. This frequent ‘recalling' of their children exacerbated parents' mental stress.

‘*…My son has a number of health challenges, and I get a lot of calls from school, whether it's about his eating habits or his behavior issues... They called me even more after COVID, I did everything I could to cooperate with schools, he takes his own lunch box and prescriptions for the medicine he is taking, and I asked them if they could stop calling me for things I have explained numerous times, but I still get calls if the nurse who knows my son* *was not at school that day and they want me to take him home just in case…"(* Parent 6, mother of a 7-year-old boy with ASD)

The experiences and hardships of participating parents demonstrate that COVID-19 restrictions have had a detrimental influence on the mental health of immigrant parents of children with ASD. Additionally, responses suggest that parents suffered compounded anxiety, stress, and fatigue as a result of the resulting changes to school policy and staff shortages in both public and private sectors which play important roles in providing services and intervention practices to families of children with ASD.

6.8.3 Within the Interactional Meso-System of Immigrant Families

The parents' descriptions of their experiences selecting services for their children who had ASD provided the basis for the links that exist between the various microsystems, such as those that exist between the family and the child's teachers and those that exist between the families and their children's classmates.

The Communication with School Influences Immigrant Parents and Their Choices

It is clear from the responses that parents gave to the questions about the services that their children received that the number of services that were provided at school (6 different types of services, 26 times mentioned in total) outnumbered the services that were provided outside of the school system (6 types of services, 14 times of being mentioned in total). In deciding the kind of services, hours of service, and substance of services, parents have many contacts with the school, some of which occur during annual or tri-annal IEP meetings, some in one-on-one contact with teachers and parents, and some with school administration, such as the principals of schools. It is apparent from the parent interviews that the process and outcomes of this communication have affected parent satisfaction with services as well as their choices toward different services.

In addition, the COVID-19 pandemics was a crucial setting for this research, and the COVID-19 pandemics was shown to have contributed to a general trend of decreased communication between schools and immigrant parents, according to the interviewees.

1) Miscommunication Due to the Shift from In-person to Online Model

All the parents who took part in the study spoke about the kindness and professionalism shown by practitioners (e.g., nurses, schoolteachers, and intervention providers) who were particularly helpful to them, as well as the positive impact that this kindness and professionalism had on their own as well as on their children with ASD. However, some participants (6 out of 13) in this study reported a rising number of miscommunications that caused mental stress that occurred when they communicated with schools regarding the education plan of their children, and parents ascribed the increasing number of miscommunications to a shift in the way they communicate, from face-to-face meetings in the past to online meetings in the present, which compounded their difficulty communicating with the school.

'*…We had a discussion with the school district during COVID-19 about their decision to lay off more than 20 special education instructors because they thought it would be a waste of money when school was closed, and you can imagine how furious we were... And online meetings make everything much more difficult; I mean, it's always more productive and related when you chat to someone face to face, but online meetings now feel like you're talking to your computer.''* (Parent 5, mother of a 9-year-old boy with ASD)

Additionally, parents mentioned how, due to the limits of online meetings, teachers occasionally logged off and never returned, or abruptly ended the conference when the time went off, even though the meeting agenda was not completely covered, which made them feel disrespected and stressed as if it had something to do with them being not proficient in English.

'*…I remember one time when we had an annual IEP meeting, and we were in the middle of it, and the teacher simply told me the time was up for this meeting, and she had another meeting to catch up, so we just finished it like that…*" (Parent 7, mother of a 17-year-old girl with ASD)

'*…You know how sometimes you can't find the right word to communicate your feelings in a Zoom meeting or over the phone coz you cannot use your body language to get yourself understood, and you stammer and have to say something to fill the silence, and you said something that isn't exactly what you meant to say...*"(Parent 9, mother of a 9-year-old boy with ASD)

Even though immigrant parents demonstrated remarkable resilience in dealing with the pandemic-related restrictions, the findings revealed that as the model of communication with schools regarding the education of their children shifted from in-person to online, the stress experienced by immigrant parents grew steadily worse.

2) Teachers' Attitudes Play an Important Role

According to parents, teachers who work closely with their children at schools are important information sources, and parents' perceptions toward teachers' attitudes impact, to some extent, their evaluations of school services and their selection of services both inside and outside school.

For example, Parent 12, mother of a 15-year-old girl with ASD who immigrated from Germany, talked about how she valued the services of the school where her daughter enrolled differently because of different attitudes they perceived from different teachers.

'*…. In first grade, she had a teacher. She was not so good, and she didn't care. I think she had big personal problems back then, so she did not care for the kids in the classroom. We lost nearly half a year, and she did nothing even though she could tell that my daughter couldn't read… so I started to intervene and went there and had a meeting with her about my daughter…*'

'*…everything started getting better because she got, she has a very nice uh speech therapist and a second language teacher, she was very helpful in the special classroom...but I think this(note: the unsuccessful service experience) was more because of problems with the previous teacher; if we had another teacher back then, maybe she or he would have done something with my daughter, so this is not a system failure, but a failure of a teacher'.*
(Parent 12, mother of a 15-year-old girl with ASD)

Also, parents reported that they would not complain or gripe about the services provided by the school even if they did not find the services provided by the school to be very satisfactory. This was the case so long as the parents believed that the teachers were trying to assist their children with ASD, especially in the context of the COVID-19 pandemic outbreak that occurred all over the world, causing shutdowns of facilities and services. Some parents expressed that they could empathize with the challenging situations that teachers find themselves in as a direct result of a lack of resources and support.

‘*…My son does not even have an aide helping him in the classroom…I just don’t know where the school district spent all the money on…I think they have been short staffing for quite a while since the pandemic…I really honestly, I like all the teachers you know, they really put their hearts to my son, like, all their best. I can feel it. But, you know, it's the result. It's about the lack of like, you know, give them enough help…I mean I bet that even teachers having a hard time…*’ (Parent 10, mother of a 9-year-old boy with ASD)

Some parents also said that they feel the quality of IEP services at school is directly proportional to the competence of the teachers. For instance, Parent 6, who is also a teacher at a public school, feels that the quality of school services is closely tied to the teachers themselves.

*‘…But I'm just from my experience as a teacher, I have seen teachers working on IEPs, so…it is really hard to estimate how much a student could benefit from their IEP; I mean, it really depends on who is your teacher and how the teacher works…I mean, of course, the situation of the child matters, but the quality of service and the teacher's personality are also very relevant…’(*Parent 6, mother of a 7-year-old boy with ASD).

The criteria for rating a teacher as "a good teacher" go beyond how well they did in terms of the contents covered in IEP services, according to the accounts of parents. It also sometimes includes the genuine care from teachers that parents sense for the development of their children who have ASD. For example, Parent 13, a local parent advocacy activist in New York, emphasized the assistance and reassurance he received from a teacher at his son's school during the time when the families were uncertain and hesitant about the path during the transition from senior high school to early adulthood for their son who had severe autism. This occurred when the families were deciding what course of action to take for their son with severe autism during this time period.

'…Teachers may occasionally talk with me privately and discuss subjects that they would not normally discuss with parents... One of their school psychologists approached me and asked, 'Have you ever thought about this?' 'He (Note: he refers to parent 13's son) presently appears to be having no problem at school, and there are staff and teachers assisting him so he can read, write, and mingle with others, but he will receive considerably less care if you insist on getting him into college,' he stated... What he stated prompted me to reconsider our previous decision that he, like his classmates, should attend college after high school. His words made a lot of sense to me, so we abandoned the initial idea and got more practical, enrolling him in a vocational training program in New York.…' (Parent 13, father of a 22-year-old with ASD)

It is apparent from the parents' accounts that the attitude of the teachers, as one of the people most closely related to their child's daily learning life, and their relationship with the parents, as well as the parents' perceived concern from the teachers for their children with ASD, play a significant role in the parents' selection and evaluation of school services.

The Communication with Specialists Influences Immigrant Parents and Their Choices

In addition to the school-based services their children with ASD get, their parents seek services outside of school to aid in the development of their academic, social, and other important skills. In this process, parents described their positive and negative experiences with communication and contacts with experts and therapists, as well as how these interactions informed their service selections.

Parent 4, a local university employee, discussed the importance of well-planned and structured procedures and positive communication between parents and specialists to her son's early intervention. She also implied that staff changes diminished the effectiveness of a very well-organized intervention program.

‘*… There weren't many places like this clinic, and it just so happened that they belonged to the university campus hospital, so I considered myself fortunate. Because my son is the first two-year-old kid they received back then, he is also the smallest, so they give more attention to us…They have a professor as a supervisor working with his two graduate students, and we, as parents, are constantly engaged. Because my son was quite unstable at the time, and when people didn't understand him, he would rapidly make a scene, such as self-injury, hitting his head, and other such behaviors. They were planning to use my son in this clinic to build a more general procedure, so the professor and two graduate students met weekly for my son’s case, and the professor participated in the intervention on Fridays…we had this schedule of intervention of five days a week, two hours a day, for a year, then the professor faded away from the program and stopped showing up in the sessions…then his two students gradually went to work somewhere else, and the intervention as a whole was not effective as before.’*(Parent 4, mother of an 8-year-old with ASD)

Additionally, parent 4 acknowledged having arguments with a BCBA who supervised his son’s case regarding the goals set up during intervention sections, which resulted in poor outcomes for the service.

‘*…The second year, the person in charge of my son's case changed, and we had a lot of disagreements with his ideas. There were also a lot of disagreements…he has set up objectives for my son, but my son was particularly resistive that year. We don't agree on his objectives because I know that if he is forced to do anything he doesn't want to do, he will become agitated and develop behavioral difficulties. However, even though we did not agree 100% with the supervisor, we adopted them and participated in the intervention process together, which was fine at first, but as his emotional problems became more serious and serious during the implementation of the goals, I sensed the supervisor gradually became less patient, and the therapist who actually implemented the goals did not seem as happy and gentle as before, so we gave it up after 1 year.’* (Parent 4, mother of an 8-year-old with ASD)

Because behavior-based intervention is one of the most frequently mentioned services both inside (1 time mentioned) and outside (5 times mentioned) schools, parents expressed their opinions toward the behavior-based intervention service during interviews, which is considered the mainstream and data-supported intervention method in the field of autism.

However, during the interview, many parents have disagreements with the implementation of behavior-based intervention by various therapists and experts, despite the fact that they feel the fundamental concepts of behavior-based intervention are beneficial to their children who have ASD.

‘*…The therapists there are meant to be quite professional; I've heard that they've all been trained by BCBA, and are supervised by a licensed BCBA, and they showed me they gather data in a quite professional way... I thought it was a good fit at first, but by the second year I couldn't stand it because they used candy as the only reinforcer in the actual process, but I just insisted from the start that we should not give him candy, and I suggested them,* *saying could we use other methods to reinforce, because he was seeing a dentist, and the dentist said he had a lot of problems with his teeth, and suggested that we should not give him candies. But at school, because candy is reinforced and kept in plain sight, he becomes obsessed with it. When he sees other kids eating it, he goes over and snatches it, and the behavior problem starts. Then this BCBA stated they wanted to fix this behavior problem again, and they came to me for a meeting and continued telling me that their hypothesis was that in order for him not to take other people's sweets, I needed to offer him more candy at home. That seemed to make no sense to me at all.' (*Parent 2, mother of a 10-year-old boy with ASD)

Even though none of the immigrant parents who participated in this study indicated they themselves being refused because of language reasons, they report that there are some instances in which concerns over their linguistic ability from service providers might have prevented them from gaining access to ABA treatments for their children.

'*…Then, an ABA company refused and rejected me, and that is an ABA company with a high rating. They came over and evaluated him; soon after, we were told that they could not provide service to my son because he may not understand English. I feel very sad, and I wanted to argue that just because his language is limited does not mean he can't learn slowly in the future, right? Just because he doesn't comprehend English now doesn't mean he can't learn it slowly in the future. Besides, we speak English, and we could be by his side during the sessions, but we were still turned down by that company.'* (Parent 5, mother of a 9-year-old boy with ASD).

There are other parents who have stated that their children have benefited from behavior-based intervention and that this service has allowed their children to make progress in domains that the parents consider to be crucial for their children.

'*… Eventually, the main reason I selected ABA was because he was receiving PRT at the time, and he was so comfortable with the protocol and everything, and he pulled pranks on his therapist, and you know, when you get to the top of the hill, you either remain there or fall down. So, back then, I believe we needed to improve it, level it up. That is why we switched to it (Note: ABA-based intervention) ... It works wonderfully for him, but I know that ABA does not work for other parents' children. I guess it's partially depending on their children's conditions, you know, it's like the same clothes, it may be comfy in one person and itchy in another, you know?*' (Parent 10, mother of a 9-year-old boy with ASD)

'*…We started at the tri-county office and were sent to floor time, which was not appropriate for him except for one of the therapists there who was able to connect with him in a very particular way so that he was ready to communicate with her... However, my son refused to interact with the other children there, and he was unable to obtain the advancement that we desired for him... So, we stopped after a year and went to Star, which changed everything! His emotions are a lot more stable than they were before, and I am grateful to his therapist.*' (Parent 9, mother of a 9-year-old boy with ASD).

It is clear from the parents' narratives that they face challenges in identifying suitable services for their children with ASD, and communications occurring in this seeking process with intervention service providers can either exacerbate or alleviate these challenges. Additionally, these interactions might have altered their expectations and evaluations of services.

The Expectations of Immigrant Parents for Schools Influenced Parents' Choices to Service

When immigrant parents were asked about their experiences, they indicated that they held a variety of expectations toward schools in terms of "what schools are supposed to provide for children with special needs." As a result of these differences, immigrant parents have made a variety of choices regarding the services that they choose at IEP meetings.

1) Parents' Expectations Differ

'*…I think, sometimes parents do not want to admit it(* Note: difficulties include falling behind academically and having behavioral problems) *is all because of the reality of their children, and then feel that it is because the teacher did not do well in school, but as a parent, you should accept that your children as they are, you cannot always blame the teachers or schools for not doing a good job…also, parents should not rely on all their hopes in the school teacher, so I think family education is still the most important…In reality, even if you attend a very good school district with several service alternatives if the child does not comply, teachers are unable to intervene, correct? If other children can adjust, why can't yours? Parents must change their perspective…Now since the academic standards set by the school for him are extremely low, I tutor him at home by myself, and we did not discuss it with the school, we just give him extra work at home, because I think teachers must have had their own teaching arrangements, we cannot always put pressure on the teachers…' (* Parent 11, mother of a 7-year-old with ASD)

It appears that parent 11, a Hong Kong immigrant, took a cooperative and stoic attitude when discussing her services choices, which is consistent with findings of previous researchers that there is a strong and stoic trend in Asian culture in which self-sacrifice without complaining is viewed as expected and even necessary (e.g., Poon-McBrayer et al., 2014; Zhang & Chen, 2021). According to the findings of this study, however, parents who immigrated to the United States from Asia do not always take a cooperative manner arising from the 'stoic cultural trait.' Sometimes it could be their beliefs about the roles of schools, particular incidences that happened to their children, or the limitations posed on them associated with their status as stipulated by the immigration laws in the United States.

'*…The nicest thing about the United States is that the teachers are aware of autism, which made my life simpler... He enjoys school, but it is also dependent on the teacher. So, in sixth grade, his instructor was terrible. So, it was difficult for him at the time since he didn't want to go to school. Also, there is the question of openness in instructors and instruction. Because the school never formally informed me that we had various teachers, I got the impression that every time I go to school, there is a new person there... And I don't see how individuals with a high school certificate can work with my son at school...because it's impossible in Korea. Teaching is an extremely competitive career, and instructors are expected to have master's degrees or higher and to be well-respected...therefore, I am no longer interested in requesting help because there are few resources, and there is so much that they could do... Services, like facilities, are quite antiquated. I'm not sure when they cleaned the carpet or the air conditioner... These are expressly stated as legislation in Korea... That is really unprofessional here, in my opinion.…*' (Parent 1, mother of a 14-year-old boy with ASD).

Parents of children with ASD may, on occasion, seek assistance that is tied to their child's medical condition, and the school responds with techniques that are appropriate to their needs. This is due to the children's unique behavioral and physical circumstances.

'*…He gets a red rash on his body from time to time since he is sensitive to dust and food in the surroundings. But it fades rapidly. We also went to school with the doctor's diagnosis and descriptions and discussed the problem with them. However, school nurses change often, so we frequently receive calls from the school for the same reason… I believe the school nurses would find us bothersome because they would continually be asking us if we had any follow-up or whatever… we prepared lunch for him specifically to avoid trouble, so he wouldn't have to eat school food, but even so, he sometimes still has symptoms….and now he has found out, that as long as he said he wasn't feeling well, the nurse would call me, and he could go home and not have to go to school, so he could possibly use the opportunity to tell this kind of lie. So, I've contacted the school several times, saying that this is his condition, that if it is possible that they could stop calling me for this reason because as soon as he calls, I have to pick him up and bring him back, which would encourage him to lie, but this problem is also not solved.*' (Parent 6, mother of a 7-year-old boy with ASD).

In addition, parents implied that they did take into consideration diversity and ethnic background when making decisions, particularly decisions pertaining to the services provided by schools, when they made choices of schools.

'*…We relocated to our present school district specifically for him to attend school. I'm not suggesting that the Asian community will necessarily be more tolerant of our child; I mostly want to move to a location where we can blend; for example, we used to live in a predominately Hispanic neighborhood, and I feel as if there is no way for us to integrate, even if they were more accepting of our children.*' (Parent 5, mother of a 9-year-old boy with ASD).

As a result, immigrant parents stated that their expectations for schools affected the services that they selected for their children. When asked about their concerns during the process of seeking services, some parents gave the impression that their immigration status and the limitations posed on that particular situation also constitute an important factor when selecting the "good service" they believe is appropriate for their children.

'*…this semester, her teacher told me, you can then go to help her apply for services (*Note: transition services after 10th grade*), I checked, and found this problem, because of our status (*Note: green card is being approved*), this service is temporarily not available… and then made me very tangled, this teacher is a nice person, but she does not understand immigration law, I also consulted with the school district, but they didn't know what to do either ...I then submitted a letter to the government describing my situation, but no one responded yet.*'(Parent 7, mother of a 17-year-old with ASD).

2) Parents' Career Affecting Their Choices When Interacting with Schools

During the course of the interviews, I came to the realization that the parent's place of employment influenced both their interactions with the school and their assessments of the services provided. Their evaluation and choice of services were significantly influenced by the level of knowledge they possessed about the field of special education as well as the educational system operated in the United States.

'*…I'm doing really well in this (*note: selecting the correct school and services for her daughter*) is mostly because I am studying this major (*note: special education major*). So, I understood what to do to prepare and how to arrange her, which was one of the advantages of my major. Her learning environment, on the other hand, somewhat overlaps with mine in* *that I have done internships every semester since my second year, and the school where I interned is in the school district where she was*.' (Parent 7, mother of a 17-year-old with ASD)

'…*And I noticed how special education teachers were working with IEPs because I was at the school... I am currently teaching Chinese at a private middle school, but I previously worked as a substitute teacher in a public middle school for four years. So, I have had the opportunities to work with, although indirectly, with, special education teachers when they made goals for students with special needs…so I learned early on that IEPs are crucial for children with autism.'* (Parent 6, mother of 7-year-old boy with ASD)

Parents who are unfamiliar with the special education system exhibit feelings of confusion as well as the untrust that naturally comes along with it.

'…*Because at first, I came over here alone with my children, I couldn't figure out how the system worked, because the gap between here and Taiwan is extremely significant. Then I discovered that IEP services by myself, I have a hunch that unless you actively inquire, nobody will be especially active to inform you which services you may apply for…*' (Parent 5, mother of 9-year-old boy with ASD)

Parent 13, a leader in a local parental advocacy group, shared his story about his experiences about 15 years ago in New York, when he and his wife, who were new immigrants to the United States at the time, were trying to put their son with ASD into a suitable public school and looking for the right services for him.

'…*We had just moved to the United States back then, and my wife and I had to work full-time… A month and a half after he went to that special school, the teacher called us for a* *meeting, and the meeting was mainly she talked about how our child was not good, not suitable for this school, and that he could not stay here, she left as soon as finishing saying that. We were stunned at the moment, because if special education school is not the right place, where else could he go? My wife was crying at the moment. Later, a math teacher informed me that there is a special school for autism, and that place could be a better fit for my son…'* (Parent 13, father of a 22-year-old with ASD)

Consequently, within the interactional mesosystem, parents' communications with schools and specialists who work for schools and outside school systems, as well as parents' expectations regarding schools and school services, play crucial roles in the process of parents seeking 'good services' for their children with ASD. In the meantime, interactions with people who work directly with families and children are impacted by parents' careers, their understanding of the special education system in the United States, their immigration status, and their prior experiences in their home countries.

6.8.4 Within the Exo- and Macrosystem of Immigrant Families

The Role Immigrant Community Plays

When asked about their experience navigating the special education system in the United States and searching for appropriate services for their children, all 13 immigrant parents described the support they received from parents' online groups for identifying appropriate services, while none of them mentioned local immigrant self-organized associations in their towns, such as churches, colleague groups, or interest clubs. When 3 parents were asked about their interactions with local immigrant populations of the same ethnicity, they tended to respond negatively.

‘…*So, it's not only because we're Asian that other Asian families will be especially lovely and receptive to him; I really want to place him in an environment with fewer Asian children and parents because they can be judgmental at times…*” (Parent 5, mother of a 9-year-old boy with ASD).

‘…*I like to work with laowai (a Chinese slang term for foreigners/internationals). You know, when you deal with Chinese parents, you have to be extremely careful not to insult this individual, and always be attentive if it is something offensive? You may say whatever you want to black or white parents about their children's disabilities, but you can't say anything to Chinese parents…*’ (Parent 13, father of 22-year-old with ASD)

‘…*because, you know, we're in New York, and no one will stare at you because you're acting strange... However, there are some Chinese seniors in our neighborhood who were critical of my son because he sometimes behaved out in public…*’ (Parent 13, father of 22-year-old with ASD)

‘…*and I was depressed because my neighbor started asking me questions about my son and kind of showing off her daughter that she is much more capable than my son despite the fact that her daughter is much younger... I stopped talking to her because I was so uneasy each time talking with her.…*’ (Parent 9, mother of a 9-year-old boy with ASD)

Parent 5, parent 13, and parent 9 migrated from different nations and areas to the United States, but their experiences of interacting with the communities of their individual ethnicities have striking parallels.

However, as mentioned above, all immigrant parents (13) who participated in this study talked about the help they got from other parents of children with ASD of different levels of severity and from different ethnic groups.

Parents' Group and Their Roles Among Immigrant Parents

Parents' groups, mostly online groups, were frequently highlighted when immigrant parents discussed the help they received, particularly when they initially began navigating the special education system in the United States or in their home countries.

'…*When we were all waiting outside for the treatment portions, I obtained most of the information I needed from other parents in the clinic... I had only spent a little time with him previously, so everything was new to me, and these parents were quite helpful in providing me with information on pediatricians and clinics*…" (Parent 1, mother of 14-year-old boy with ASD)

'…So, it (note: parents' group) *is not always about sharing resources, because we all live spread out across the US, and we are more like finding a place to vent and for emotional support in bad days…' (*Parent 5, mother of 9-year-old with ASD)

Parent 5 also implied in her narratives that the degree to which parents can receive assistance/support from the parent's group is associated with other factors, such as the age of their children and the severity of their condition.

'…*Later, I discovered that there were more new parents in the group, and their children were younger, so the topics they discussed were less appealing to me; for example, the topic of potty training did not interest me at all, so I spoke less and less later.'* (Parent 5, mother of 9-year-old with ASD)

Additionally, according to parents, the varying degrees of severity of children's conditions are a factor in determining whether parents could benefit from the same parent group in terms of locating suitable resources and/or assistance for their children.

'*…Thinking back, when other parents recommended the first school that I was dissatisfied with, it may have been due to a mismatch between the school and my child: If my child's level of functioning is reasonably high, that school could have been a good fit for him. It could be because the parent who recommended the school had a child with high-functioning autism…*' (Parent 2, mother of a 10-year-old boy with ASD)

'*…In fact, I'll simply say that parents of children with severe autism are extremely difficult, and many of them don't even stick around until their children are five or six years old, and they've given up inwardly, you know, right? Then many parents of high-functioning children in the group discuss subjects that make no sense to us, even though some individuals in the group say there is hope for our children, but none of us truly believe what they say…*' (Parent 4, mother of 8-year-old boy with ASD)

According to parent 4, parents of children with moderate to severe ASD typically end up forming their own groups separate from those of parents of children with mild to moderate ASD due to similar life challenges and mutual emotional support, and her narratives echo those of other parents who have experienced similar situations.

'… It was difficult for me to gain this knowledge because I had never met a parent of children with autism. I mean, parents with children in various situations might not be as interested in this knowledge as I am. Later, I met other parents of children with ASD, and they informed me what kind of institution to seek, and I gradually became acquainted with

these difficulties. Following that, I worked with the school district for my son myself…' (Parent 11, mother of an 8-year-old boy with ASD)

'…*It's as though long-term disease forces patients to become their own doctors. So, when other parents mentioned services, we eventually realized that it had to be the one that fit his circumstances, so we won't just take other people's choices for granted because we have gone through a wide range of services and therapies provided by other parents…*' (Parent 6, mother of 8-year-old boy with ASD)

To summarize, parents reported that other parents of children with ASD of a similar level of severity influence their navigation toward appropriate services. It also appears that groups of parents provide a stronger bond than groups based on ethnic origins or immigrant communities. When asked about their expectations for their children in the future as well as their dissatisfaction toward special education services both in their home country as well as in the United States, the answers that parents provided implied the existence of conflicts and congruity of their perceptions toward cultural beliefs of disabilities in both their home cultures as well as in their host cultures (culture of the United States).

Home Cultures and Host Cultures Toward ASD

1) Perceived Home Cultural Perspectives toward ASD

When asked about their experiences, immigrant parents talked about their understanding of their home cultures, especially those with disabilities or ASD. Because the presentation of findings in this part pertains to culture and the interpretation and comprehension of culture, I include their origin country of immigration and current length (in years) of immigration to the United States next to the parent interview excerpt.

8 out of 13 parents discussed their understanding and experiences of their home cultures in relation to disability or ASD. Lack of social support and sentiments of shame/aversion to acceptance due to the disability of their children are a recurring theme.

'…*You know, there is no special education in my country; you may hire a private tutor at home, but there are no special education programs in schools... My husband blamed me for suggesting he might have autism because he was embarrassed to have a child with mental issues*…' (Parent 9, mother of a 9-year-old boy with ASD, immigrated from a country in South America for over 10 years).

'…*I was very impressed because of the system of inclusion; you don't have it in Germany. Your child can not go to regular school because they think it will be disturbing…so you have the special schools, but they don't interact with other children at all. Yeah, I feel in this part, Germany is so falling behind*…' (Parent 12, mother of a 16-year-old girl with ASD, immigrated from Germany for around 8 years)

'…*Why are Hong Kong, the United Kingdom, and the United States so tolerant of children with disabilities? They legislated early on and took this very seriously because they are not the same for individuals with disabilities, and the parents in these countries pushed for these rights. What makes China different? Because no one is willing to fight for it. You must battle for your own rights and interests, and only by doing so gradually can autistic children be respected and protected*…' (Parent 11, mother of an 8-year-old boy with ASD, originated from HK and immigrated from UK to the US for over 5 years)

In addition to the reoccurring themes discussed previously, immigrant parents also highlighted cultural disparities resulting from differences in educational systems.

‘…*Because our private school system in Korea is far superior to public education. If a child is not typical, parents will seek treatment at private institutions because public schools do not provide any assistance*…’ (Parent 1, mother of a 14-year-old boy with ASD, immigrated from Korea for over 5 years)

‘…*The teacher at the school she attended advised us not to send her here because she would cause disruption...So, we've been suffering since she began preschool since school has been so boring. We have been ejected by a variety of schools*…’ (Parent 7, mother of a 17-year-old girl with ASD, immigrated from China for less than 5 years)

‘…*We didn't have special education there, which is good if you have the money to hire a private tutor for your child, but not in public school*…” (Parent 10, mother of a 9-year-old boy with ASD, immigrated from a Persian country over 10 years ago)

Similarly, parents talked about the attitudes they've experienced in hospitals, families and communities regarding ASD and people who have disabilities.

‘…*My mother took him to a local brain hospital when he was around 2 years old, and he was diagnosed with ASD. my mother claimed she couldn't take it and handle it, and she doesn't believe things about ASD... and his father later took him back to the United States*…” (Parent 8, mother of a 9-year-old with ASD, immigrated from China over 10 years)

‘…*I went to his school because he was always bullied there, and even though the school is well-known, I tried to talk to the principal about it, but the principal simply drove away and ignored me. The other parents were aware of it, but they all seemed to believe I shouldn't have bothered with the school*…’ (Parent 3, mother of a 22-year-old with ASD, immigrated to the US for 8 years).

Immigrant parents also discussed how they felt their native cultures were represented in the host nation (the United States). For example, Parent 13, an active advocate for the right to disability communities in the New York region, the father of a boy with ASD who is now an adult, and the parent with the longest immigration history among the other 13 parents, said that most of his perceptions came from his interactions with Chinese families from various walks of life in the United States that Chinese parents are judging when they find children with special needs around

'*…because, you know, we're in New York, and no one will stare at you because you're acting strange... However, there are some Chinese seniors in our neighborhood who were critical of my son because he sometimes behaved out in public…*' (Parent 13, father of a 22-year-old with ASD, immigrated to the United States in 1980s)

'*…Yes, there are still occasions when I think the Chinese community's love of high education and blind worship of highly educated people is something I really despise. And the glorification of excellent performance. This is tied to our cultural tradition, so many things we are especially careful about, especially within the Chinese community, because our goal is to help them, not to condemn them…But I am also Chinese, and thousands of years of tradition are impossible to erase, especially in our lives when we face such setbacks and hardships, these discriminations come out all of a sudden, if you are very smooth, you have no conflicts in the community, but once something happens, especially like us (*note: have a child with disabilities*), you will see a lot of discrimination in the surrounding Chinese community, such as People avoid your kids...'* (Parent 13, father of 22-year-old with ASD, immigrated to the United States since 1980s)

In general, when parents discussed their understandings of home cultures toward disabilities, they encountered in their home countries or in ethnicity-based local communities organized at the host cultures, they used a negative tone in their narratives, and some even reported that the cultures were one of the primary reasons they chose to immigrate to the United States.

2) Perceived Host Cultural Perspectives toward ASD

When all 13 participants discussed their experiences enrolling their children with ASD into regular public schools in the United States, a consistent theme emerged: their interactions with the public schools where their children with ASD were enrolled. Immigrant parents talked about their experiences with the attitudes that educators, professionals, and teachers who work directly with families have had toward them or their children.

All 13 of immigrant parents who had immigrated to the country spoke positively about the welcoming environment they experienced in the public schools.

'*…We had a course called 'The Cornerstone of That Special Education,' and then chapter 4 talked about family support, and the a teacher of the course played a video about community support; I really couldn't hold the tears when the video was rolling, you know? It shows the family, the professionals, and the kind of understanding and tolerance they have toward the youngsters with severe disabilities in the school and communities that are truly lacking in China… I returned and couldn't stop crying since I remembered how no one cared or assisted me throughout my previous years back in China. I cried for quite some time…*' (Parent 7, mother of a 17-year-old girl with ASD, immigrated to the United States in 2017)

‘…*I believe that the environment here encourages children's independence and self-regulation and that the schools allow students to find their own resources…I mean one of my son's goals was to be able to explore resources on his own. He grew up in an environment where was repressive and sometimes humiliating to him, so I believe the entire education system here is quite fair and helpful for him to gain the confidence about himself...*’ (Parent 3, mother of 22-year-old with ASD, immigrated to the United States for 8 years)

However, immigrant parents (3 out of 13 participants) who tried private schools in the United States reported different stories that in the United States, where public discourse on disability inclusion is so prevalent, discrimination and exclusion remain where AERA does not reach.

‘…*The principal did not want him, but he also did not want to refund our tuition. So, he devised a strategy of calling me every day and whining about my son in the hopes that I would drop out and they would not have to repay me…*” (Parent 5, mother of an 8-year-old with ASD, immigrated to the United States over 10 years)

‘…*The school told me, either you hire someone to help him or come over and support him myself, and then the therapist I hired was pregnant, and I had to accompany him to class from time to time… For example, one time, I had just ended a meeting when the school phoned me; I called back, and the school said, you have to come over, he did not listen. Then I went over, it was winter, children were playing outside, and I was wearing pants and heels from a business meeting, they(*note: teachers*) told me all children must go outside to play, and you must support him, I remember the snow was very thick outside, they didn't care about me, they told me, 'you have to go out,' I had to wear high heels, feet into the snow, the snow was probably up to my knees. Later, after two more similar incidents, I suddenly felt* *that this thing was really humiliating for me, that they simply do not care what parents think, and then I could not stand it, I wondered why I spent this money in this case, and I now believe that they are forcing me to withdraw from that school, but they did not want to sound that way.'* (Parent 2, mother of an 8-year-old with ASD, immigrated to the United States for over 10 years)

The only parent of the 3 who had a pleasant private school experience also mentioned other issues, such as a lack of inclusion within private schools.

'*…Then I discovered a school for high-functioning children with ASD, However, you need to take an exam for admission screening. At the time, I learned that they only accepted students from the fourth grade and up. The school had more support than the public school did, but it lacked the regular school atmosphere where children could mingle and converse, and it felt like a hospital inside…*' (Parent 8, mother of a 9-year-old with ASD, immigrated to the United States for over 10 years)

In addition, 4 out of 13 participants (parents 2, 7, 8, and 10) noted variations in special education services based on economic development levels between states. Based on their narratives, it appears that social views regarding ASD or disability in general are not only connected with a 'moral value,' but are also tied to the economic resources in the local community.

'...We were in Detroit at that time, which you may have heard of; this city has very limited public services; my son was in a special class at the time, and there were three substitute teachers in a class with 15-16 students. Further than the IEP, no other services were offered. And the IEP was a very general plan that wasn't specifically tailored to his requirements. But

I didn't realize it at the time. But I was so dissatisfied with the service that I wanted to leave. It's true that the services were so inadequate that the city of Detroit went bankrupt, approximately in 2015, and then the teachers went on strike quite often, and the kids were all on vacation following the strike. Then, to make matters worse, the person in charge of special education in that school district was arrested and imprisoned because of accusations of corruption. That year was thus the worst. You know, it's -30 degrees Celsius in the winter of Detroit. However, there was no heat in the classrooms. That's how terrible it was…' (Parent 8, mother of a 9-year-old with ASD, immigrated to the United States for over 10 years)

'*…we were in Oregon; I received the referral from his pediatrician…we went through the entire procedure. He had a speech delay and we only got a speech service that was like an old lady coming to our house once a week to work with him, they said based on where we lived back then as well as his diagnosis of ASD with speech delay, this was the only service they could provide...so we moved over here to Santa Barbara because the intervention services and all that are way better than that in Oregon*.'(Parent 10, mother of a 9-year-old with ASD, immigrated to the United States for over 10 years)

In addition to the variations in services as well as the perceived social attitudes toward disability and ASD that exist between states, parents also discussed variations that exist within a state. These variations were thought to be associated with the different demographic compositions of the local populations. Parent 7, an immigrant mother who is now a teacher of students with special needs, shared some of her thoughts on the difference that she has observed.

‘…*Last year, I was in a city in South Georgia that is less economically developed than I am now, and I worked in that school district, in that school district, about 95 percent of students are African Americans… even though that city is also a southern transit center, the economic conditions are definitely worse…Then I met some special education teachers, some of them are not full-time special education teachers, for example, they might be in charge of a special classroom but at the same time they teach courses for regular classrooms…they are trained as special education teachers, and I often get the impression that when they tackled these unique issues with children with special needs, they simply just did the minimum to get by and not seriously handled it.’* (Parent 7, mother of a 17-year-old girl with ASD, immigrated to the United States in 2017)

Among all 13 immigrant parents of children with ASD, 4 parents (parents 5, 7, 12, and 13) talked about their efforts of advocacy for disability communities for their children and others who are in special needs in their cities or school districts. As recounted by these parents, these advocacy initiatives aim to increase local public knowledge of disability rights.

‘…*Later, it appears to be because of what happened to the parents, and then the parents decided that we should group up together to make our voice heard, and I believe unity is strength, right?*’ (Parent 5, mother of an 8-year-old with ASD, immigrated to the United States over 10 years)

‘…*the issue that many Asian parents confront is that they are terrified of losing face. Many individuals are scared to speak out about their needs when they have to use the words disability or ASD, and there is a severe dearth of Chinese resources in the English context. So, what we're doing now is helping all the parents who are influenced by Asian culture. For example, this year, I'm working on a project in New York State regarding social sex* *education for children with autism, particularly teens. I'm going to incorporate cultural elements into the materials, and we're all set to begin the first session this week, with the possibility of expanding it to additional states in the future…*' (Parent 13, father of 22-year-old with ASD, immigrated to the United States since the 1980s)

6.8.5 Conclusions to Study 2

To conclude, according to the findings, the process by which immigrant parents select services for their children who have ASD is a complicated one, and their conception of what constitutes a good service is the product of a multi-faceted and very individual experience. The process of navigating the special education system in the United States was a social process that involved the exchange and interaction between and within various players and structures, such as parents, special education practitioners, and communities.

Chapter VII Discussion

7.1 Overview

Through the theoretical lenses of habitus, social capital, and cultural capital, the focus of this study is on elucidating the 'objective' reality of immigrant parents' service selection experiences. Two studies are incorporated within this project: Study 1 is a systematic review of 31 including studies on ethnic minority parents and their choices of services for their children with autism spectrum disorder (ASD). Study 2 is a qualitative study from a phenomenological perspective on the experiences of 13 immigrant parents navigating the special education system in the United States. By analyzing and synthesizing findings from two studies through the conceptual lens of social status and power relations (Bourdieu, 1986), this project aims to investigate the subjective experiences of social structures that immigrant parents must navigate when advocating for their children with ASD.

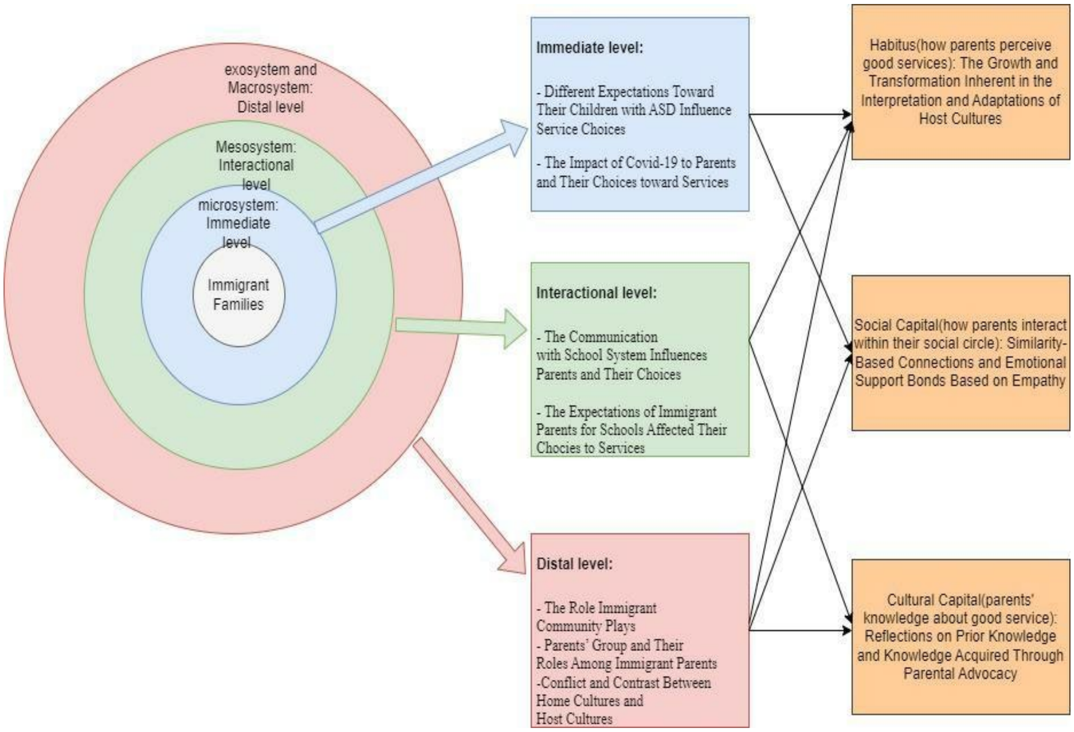
In this chapter, I expand on the presented findings in light of theoretical frameworks of social status and power relations developed by Bourdieu (1986) and other researchers (e.g., Bystrianska, 2018; Guzmán et al.,2018; Yosso, 2015) in the field of social capitalization strategies (capital theories) as well as the socially structured agents (habitus). Based on that, I further propose a model of service selection/rating of immigrant parents, which is embedded in the interaction process with major players under the interwoven cultural (home and host) contexts, as is shown in Figure 6.

7.2 Discussion and Interpretation of the Research Findings

The core categories ‘social capital’, ‘cultural capital’ and ‘habitus were generated and abstracted from the research finding data and form a basis from which the main categories can be understood. In this study, participants described and shared their experiences as immigrant parents navigating the special education system in the United States as identifying and looking for ‘good service’ for their children with ASD. As stated in chapter 3, which examines the 'internal' attributes of parents, Bourdieu's capital and habitus theories view parental behavior as a result of interaction between parents and the 'external' societal system in which they live, whereas the ecological theory of parenting (Bronfenbrenner,1979) assists in interpreting parents' experiences within a contextual ecological system. As a result, the ecological system will not be included in the discussion section's categories as a tool for conceptualizing and characterizing the social environment in this study. As stated in the overview, Figure 5 provides an overview of categories of discussion and how these categories arose from finding, and Figure 6 under section 6.3, suggests a model of interactions of different stakeholder players (immigrant parents, schoolteachers, professionals, and parents' groups) in the process of searching for and identifying good services based on the categories of discussion.

Finally, the difficulty inherent in exporting and elucidating concepts relating to the subjective experiences of parents is accurately constructing and reflecting parents' perceptions from the researcher's perspective, and an attempt will be made to clarify this potential validity challenge by member checking with each participant when the project is complete or any manuscript aiming to be published, as suggested by Creswell and Miller (2000). According to Creswell and Miller (2000), member checking is the act of returning information to the participants so they may participate in the systematic process of authenticating the narrative account.

Figure 5 Topics of discussion



7.2.1 Category 1: Habitus: The Development and Transformation Inherent in the Interpretation to Host Cultures and Adaptations of Home Cultures (How Immigrant Parents Perceive a 'Good Service')

Home Cultures Toward Disability Impacted Immigrant Parents' Service Choices

The results of the current research study suggest that immigrant parents have expressed the deeply ingrained and pervasive stigma and shame that is associated with the socialization of views toward persons with disabilities in their home countries. This is consistent with the substantial body of research that documents the shame-socialized culture that is firmly embedded in several different civilizations (e.g., Chang & Hsu, 2007; Holroyd, 2003; Fong et al., 2021). For instance, Fong and colleagues (2021) reported that according to their studies, one of the primary reasons participants (13 immigrant parents of children with ASD from South Korea to Canada) reported stigma and discrimination as one of the reasons they decided to 'escape' from South Korea was because they were afraid of being discriminated for their children's conditions.

However, different from many other studies that came before it, this study places a primary emphasis on the ways in which immigrant and minority cultures influence the perceptions, behaviors, and, most specifically, the service choices that immigrant parents make for their children who have ASD. For instance, Lindsay and colleagues (2012) suggested that healthcare and community service providers face many challenges when it comes to providing care to immigrant families. These challenges include a lack of training in culturally sensitive care, language issues, divergent perspectives of healthcare providers and immigrant parents regarding disability, and the importance of developing client and service provider relationships, as well as the need for service providers to help parents to advocate for themselves and their children. Even while their research emphasizes the significance of culturally sensitive services for minority parents, it does not explain what these culturally sensitive elements are (habitus) or how they impact relationships between parents and professionals.

According to researchers such as Cockerham (2013), these elements, originating from their habitus, shaped people's thinking, judgments, and actions, and reproduced the structure in the new society from which they originated. In the context of the present study, habitus refers to ingrained attitudes regarding disability, such as ASD, as well as understanding of what constitutes a "good service" for ASD populations. The findings of this study suggest that even though habitus was formed and shaped within a specific social context and was influenced by structural variables such as social class and educational background in their home countries, immigrant parents to a new society, bringing with them changes to these variables, develop a similar habitus within a different social background. For example, 10 of 13 participants indicated that they expected their children to achieve academic success in the future, while only 3 out of 13 participants of this study indicated that they only expected their children to live a happy life in the future. Among the 10 immigrant parents, 9 of the 10 of them were from Asian countries and regions, while 1 parent was from Iran. Consistent with previous research on Asian parents and their expectations for their children with and without disabilities (e.g., Vaughan, 1993; Pang & Richey, 2007; Zhang et al., 2022; McCabe, 2017), this finding indicates that immigrant parents of children with ASD maintained their educational expectations despite migrating to a new social and cultural milieu and the occurrence of ASD in their children.

In addition, 3 of 13 parents reported negative interactions with other immigrant parents of children without disabilities from the same countries and regions; none of the participants in this study reported assistance from local immigrant self-organized associations, corroborating the accounts of immigrant parents that they maintained academic expectations for their children, indicating a continuation of a value ingrained in their home cultures. Most of the local support that participants found beneficial came from parents in similar situations, both immigrant and non-immigrant parents.

On the surface, this finding appears to contradict earlier sociological observations that ethnicity may have a significant role in immigrants' choice of destination community. For instance, Cuba and Longino (1991) stated that members of the same or comparable ethnic group may feel more at ease relocating to neighboring regions/provinces in order to maintain their customary lifestyle. However, for this study, it focuses on a sub-group of immigrants: immigrant parents of children with ASD. Therefore, when combined with the factor of 'disability' or 'ASD,' the experiences immigrant parents reported in this study are consistent with previous research indicating that parents in certain regions were frequently blamed for their child's academic and behavioral problems and dealt with the lack of awareness of ASD as well (e.g., Yu et al., 2020).

In addition, parents whose expectations for the academic achievement of their children with ASD are high choose programs that are more aggressive or that emphasize dealing with academics such as writing and math. In addition, they tended to identify a service as "not very excellent" if they did not witness development in academic-related or future-predicting capabilities.

Nevertheless, the expectation may also be influenced by the severity of ASD and the year of immigration to the United States. For example, parent 13 of this study, who immigrated to the United States in the 1980s, discussed the process of shifting from a 'disability to ability' to a 'disability to possibility' mindset, whereas all 3 parents who said they only wanted their children to be happy have children with ASD ranging from moderate to severe levels, and their children are older(from 14 to 22) than most parents who also wanted their children's academic achievement. Since the 3 parents (parents 1, 12, and 13) are from different countries, it appears that ethnicity did not play a role in the similarities between their service preferences and ASD understandings.

Researchers found that while most immigrants seek to keep both their heritage culture and the host society's culture, moreover, this choice is not made in a vacuum: it is impacted by the attitudes and actions of the host society (e.g., Horenczyk, 1997; Berry, 1997). For example, Berry (1997) described 4 types of acculturation attitudes immigrants might develop in the process of forming habitus in the host culture: The first kind, assimilation, is defined by immigrants' desire to be in contact with members of the host society while discarding their own cultural heritage. The second type, separation, is characterized by immigrants' wish to keep most of their cultural identity while avoiding considerable engagement with the dominant host culture (often because of exclusion or discrimination); The third kind is the integration attitude, which displays a desire to keep significant elements of immigrant cultural identity and has meaningful ties with members of the host community; the fourth type is the marginalization attitude, when immigrants choose to reject both their own culture (sometimes due to enforced cultural loss) and contacts with the host majority (often because of exclusion or discrimination).

Although immigrants' attitude changes were not the focus of this study, it is shown that while describing their experiences when engaging with parties of interest, including the school instructors, special education practitioners, and individuals in their surroundings, immigrant parents' attitudes regarding service choice typically exhibit an integration process. This form of acculturation attitude is referred to in the previous paragraph as the third type of acculturation attitude, which implies that immigrant parents’ attitudes toward services stem from a combination of both habitus, one from the heritage culture and one formed in the host cultures.

In summary, as immigrant parents of children with ASD moved from one cultural sphere to another, they faced the dilemma of shifting the paradigm of disability: On the evaluation of service efficacy, they habitually relate to their heritage/home cultures regarding the desirability of academic performances, while in the course of procuring services, they are aware of, and opposed to disability prejudice and exclusion embedded in the heritage cultures. The changing of habitus may rely on objective variables such as the severity of

ASD in their children, the length of time they have been in the United States, and their interpretation of how people with disabilities live in the host country.

A Significant Part of Constructing the New Habitus is Figuring Out How People with Disabilities Live in the Host Country

In the current study, all 13 participants talked about the difference they perceived between their heritage cultures and host cultures toward people with disabilities, especially those with ASD. Despite the problem of changing the disability paradigm from heritage culture to host culture, their opinions that children with ASD need a place in inclusive education were reaffirmed and confirmed after seeing firsthand the regulations and safeguards for inclusive education in public schools under the ADEA in the United States, even though two of them were rejected from private schools, according to the 3 parents, they do not exhibit the same level of acceptance of rejection or submissive collaboration as other parents would do in countries where public comprehensive education is not required or not mandatory in practice, such as Chinese parents(Zhang et al., 2022). This indicates that people's interpretations of their surroundings have a reinforcing impact on their views/perspectives/understandings which are consistent with previous studies. For example, Bourgois and Schonberg (2009) presented their ethnographic investigations on the implementation of public policies using the idea of habitus to reflect the complexity of why people behave and feel as they do. They claimed that in order to fit into a new routine, individuals will need to develop a new sense of personal purpose and dignity by interpreting the behaviors of others.

As Bourdieu (1984) suggested, a power dynamic relation exists in social lives that various levels of society, economics, and cultural capital jointly have formed a class structure where one's own habitus is influenced by the internalized social structures including bias and traditions. Furthermore, one may become conscious of one's own prejudices as a result of these constant reflections, which are impacted by the desires of individuals in dominating social classes (Bourdieu, 1984). 8 of 13 parents expressed their understanding and experiences of their home cultures in connection to disability or ASD in the current study. Lack of social support and feelings of shame or aversion to acceptance due to the disability of their children are recurring themes, while all 13 participants spoke positively about the welcoming environment they encountered in public schools. However, 3 of 13 parents discussed the difference between public and private schools in terms of inclusive education. As a result of these ongoing reflections, this insight represents a process characterized by Bourdieu (1984) as being aware of one's own biases while establishing new habitus.

Moreover, according to Giddens' theory of structuration (1979/1982/1984) and Bourdieu's theory of practice (1977/1983/1984), people are active subjects (or players) who interpret the meanings of individual actions or the actions of groups that share common experiences happening around them and changes in their choices or behavior might occur accordingly. According to sociologists in related fields, this transformation might be seen as a cultural integration or assimilation process (e.g., Dustmann, 1996; Orlikowski, 1992). Furthermore, according to the literature on the interaction between immigrants and host cultures (e.g., Bertacchini et al, 2021; Fokkema & De Haas, 2015; Giovanis, 2020), integration into the new society also depends on the degree of exposure to the new environment and on the level at which a migrant is able to access knowledge and information about the new social structure; thus, first-generation immigrants are less likely to participate in socio-cultural activities than their descendants. In other words, as stated by Dustmann

(1996) in his research on the shift of habitus among migrants, environmental changes are crucial to the process of habituation, in which behavioral patterns alter.

The findings of the present project corroborate these past findings on the evolution and transformation of immigrant habitus. For instance, all 13 parents expressed their understandings and experiences of their home cultures in relation to disability or ASD from a variety of narrative perspectives, and study 1 suggested the significance of perceived home culture toward ASD (19%) and its impact on parents' selection to services. Furthermore, according to the narratives of parents in study 2 of this research, duration of residency and socio-economic variables, such as employment, education, and income, tend to lessen gaps in the frequency of sociocultural involvement, which is consistent with the findings of prior research (e.g., Dustmann, 1996).

The findings indicate that all 8 immigrant parents of children with ASD who had been in the United States for more than 10 years spoke about the weaknesses and strengths of the U.S. special education system and suggested some features of the U.S. special education system that differ from those in their home countries, while all 13 parents spoke about the frustrations and support they had encountered when seeking appropriate services for their children both school-based or outside of school. The 4 most notable sources of support in their accounts were as follows: schoolteachers, parents’ groups, parents’ advocacy activities, and professionals. Using the capital theory as a theoretical framework (e.g., Reed-Danahay, 2004; Shen, 2020), social scientists attempted to determine and understand how each person fits into the physical and social structure and whether and how people traverse different social subgroups. Similarly, in the present study, the accounts depicting immigrant parents' strategies for gaining, activating, and storing cultural and social capital are crucial for understanding the process of exchanging and trading with their environment.

7.2.2 Category 2: Social Capital: Similarity-based Mutual Support and Connection Bonds Based on Empathy (Whom and How Immigrant Parents Communicate for 'Good Service')

Fundamentally, social capital may be divided into three levels based on network viewpoints(e.g., Putnam 2000; Woolcock, 1998; Woolcock & Narayan, 2000). According to the network perspectives, there are three levels of social capital exchange: bonding, bridging, and linking. Bonding social capital refers to intragroup (horizontal) linkage between individuals. Bridging social capital refers to ties between individuals who differ in observable ways, such as age, socioeconomic standing, race/ethnicity, and level of education (Szreter & Woolcock, 2004). Linking social capital refers to the amount to which individuals cultivate ties with organizations and others who possess relative influence over them (e.g., to provide access to services, jobs or resources).

Findings from this study indicated that all three categories of social capital were utilized by immigrant parents in the process of locating suitable or ‘good’ resources for their children with ASD. Different from the flow of capital across various social classes implied by Bourdieu’s (1978) initial ideas, the common encounters based on their child's ASD severity level and empathy originated from shared experiences play more important roles than their social class in the exchange and application of social capital by the immigrant parents. In other words, the same or comparable severity of their child's illness (e.g., mild to moderate, moderate to severe, or the type of impairments) bound these immigrant parents together in a process of exchanging and referring information and resources in response to the common experiences.

Bonding Social Capitals Based on Similarities of Their Children

In this study, all 13 immigrant parents talked about the help they received from parents’ online or in-person groups and especially parents or parental advocacy groups who shared common experiences with them. According to parents, the varying degrees of severity of children's conditions are a factor in determining whether parents could benefit from the same parents group in terms of locating suitable resources and/or assistance for their children. For instance, parents' narratives suggested that the extent to which parents can benefit from interactions in parents' groups is related to factors such as the age of their children and the severity of their condition and that parents tend to form their own groups distinct from those of parents whose children are different from their own. In times of COVID-19 pandemics and socially constrained circumstances, these bonding behaviors based on the exchange of resources are extremely crucial. It is stated that parents feel more at ease when interacting with families facing comparable issues and that they feel less at ease when paired with parents whose children exhibit less severe ASD symptoms or higher academic functioning at school. This finding is consistent with the previous studies of parental mutual help models. For example, in early studies of parent-to-parent support groups, Ainbinder and colleagues (1998) observed that helpful comparisons occurred in parent-to-parent pairings when the supporting parent's child had more severe challenges than the referred parent's child because the referred parent gained a new perspective on his/her child's disability that was infused with feelings of gratitude coming from the downward comparison (Taylor et al., 1990). However, there are no related findings from parent support groups indicating how the parent whose child is in a poorer position feels inside and how they gain from parent-to-parent online or in-person groups.

Even among immigrant parents of different income levels, the bonding between them is not significantly reported as relating to their economic status; according to their descriptions, the most important factors connecting them in the process of social capital exchange are the similarity of their children's status and their surroundings (e.g., whether they live in the same state/area).

Bridging Social Capital Across Classes

According to Alder and Kwon (2002), bonding social capital refers to relationships between network members who are similar in some way, whereas bridging social capitals refers to relationships between people who are demonstrably dissimilar, such as in age, socioeconomic status, race or ethnicity, or education. This link may also be considered a horizontal association and is characterized by a 'heterophilic' interaction resulting from a weaker connection between various individuals. According to a related study, bonding social capital has a detrimental influence on the degree of sociability beyond the closed social circle, but bridging social capital has a favorable effect (Beugelsdijk & Smulders, 2003).

In the present study, participants reported exchanging social capital with people from demonstrably different backgrounds, such as their neighbors of different ethnic groups, other parents whose household incomes are in a different category, and native professionals with different occupations than parents. In fact, none of the 13 parents identified local immigrant self-organized associations in their communities, such as churches, colleague groups, or hobby clubs, that are typically referred to as resources due to ethnic and racial commonalities. When questioned specifically about their relationships with local immigrant groups of the same ethnicity, parents answered negatively. In other words, when immigrant parents of children with ASD seek social help, the severity of ASD of their children and the hurdles they face themselves become part of the capital exchange system which allows parents to communicate their ideas by making sense of common experiences.

This conclusion regarding the role of shared experience in the exchange of social capital is consistent with earlier research. In the literature, social capital is frequently defined as the formation of networks (e.g., Carlsson & Jacobsson, 1993) and the system affinity of individuals who perceive themselves as part of a system with shared challenges and possibilities (e.g., Alder & Kwon, 2002). The findings suggest that the significance of shared experiences to social capital originates, at least in part, from a shared belief system that elicits shared worldviews, assumptions, and expectations. This, in turn, facilitates the collective behavior of immigrant parents in identifying the most appropriate service for their children as well as their advocacy efforts during the process of navigation.

Linking Social Capital Through Cooperations with Parties of Interests

In the current research, immigrant parents were asked about their experiences navigating the special education system in the United States, including how they collaborated with institutions and individuals who have relative power over them, as well as how they related to those individuals and institutions. For instance, all 13 participants discussed their experiences with pathologists, autism advocacy groups, schools, and other specialists in the field of ASD. According to Woolcock's (2001) concept of linking social capital, people and groups can develop connections with those outside of their immediate networks who have access to power, wealth, and influence by linking social capital. This process may be viewed as the vertical component of social capital, where the capacity to harness resources, ideas, and knowledge from formal ties can be generated through alliances with powerful persons. This description of linking social capital is supported by the findings of this study since immigrant parents state that relationships with service providers, schools, and important personnel within these agencies are crucial to the success of services in their search for the best match for their children with ASD.

Researchers suggested that linking social capital is a result of the weakest relationship, but it is one of the most useful results since it offers access to and connections with power structures because it is beneficial for gaining access to help from official institutions (Woolcock, 2002; Saundry et al., 2011). Compared to bonding and bridging in the exchange of social capital, connecting social capital in the context of this study focuses on interactions between unequal parties, such as immigrant parents vs the school, immigrant parents versus professional organizations, and immigrant parents versus service providers. In this case, immigrant parents use linking social capitals to leverage resources for identifying a good service for their children, which has been more effective than personal bonding or bridging with someone outside their social circle, because by linking social capital with those service providers, in public or private sectors, the communication and interaction are much more direct and goal-oriented, such as in IEP meetings or counseling sessions with therapists.

7.2.3 Category 3: Cultural Capital: Reflections on Prior Knowledge and Knowledge Acquired Through Parental Advocacy (Immigrant Parents' Knowledge About Good Services)

As suggested by Bourdieu (1986/2011), culture capital appears in several forms: objectified cultural capital represents materials such as books and other media that inform knowledge or actions; embodied cultural capital represents disposition and taste that guide ways of acting and thinking, and institutionalized cultural capital represents conferred capital such as academic credentials with associated benefits. Using critical race theory, Yosso

(2005) further broke down and redefined cultural capital into six sub-types that are not mutually exclusive or static, but instead operate as dynamic processes that build on one another: aspirational, navigational, social, linguistic, familial, and resistant capital. Researchers of sociology studies applied the concept of cultural capital in a series of studies, including the formation and transformation of social classes as well as resource attainments.

In studies of social class, the idea of cultural capital has frequently been considered as a characteristic that distinguishes persons from different social classes. In his work on the emergency of a new middle class in occupied concession, Hilal (2022) argued that the possession of 'cultural capital' is a distinguishing characteristic of middle-class occupations, as opposed to the possession of other forms of capital, and that cultural capital refers to the high education and specialized training that individuals must acquire to qualify for middle-class occupations.

Cultural capital, like the other forms of capital developed by Bourdieu (1978) initially in traditional sociology studies, denotes a status of higher education and specialized training that individuals acquire to justify their positions in a certain class, and it is one of the forms of capital most closely associated with knowledge acquired for subjects' social standings.

In the present study, however, the idea of cultural capital has nothing to do with the socioeconomic class of the participants. The discussions of cultural capital in the present study are consistent with these arguments academics (e.g., DiMaggio & Mohr, 1985; Nash & Harker, 1992) have made that cultural capital has an effect on educational attainment. For instance, DiMaggio and Mohr (1985) contend that if a person is well endowed with cultural capital (e.g., diploma, knowledge), they will have more possibilities for particular assistance from professors and other gatekeepers, as well as greater access to contexts where cultural capital itself is valued and where information about educational opportunities is available. Similarly, qualitative research on the production/reproduction of cultural capital in educational contexts gives further information regarding parental activities in their contacts with schools. Wu (2012) notes that present school choice procedures among elite primary and middle schools need both high-level economic and cultural resources from parents. Middle-class parents in China, for instance, have a greater capacity to assist their children in accumulating cultural capital by enrolling in extracurricular classes, acquiring educational credentials, hiring tutors, becoming special talent students, and utilizing the parents' educational level and personal history (Wu, 2012). Similar findings were observed by researchers in the field of special education about the functions and utilizations of cultural capitals by parents seeking "the best" treatment or services for their children with special needs. Trainor (2010), for instance, utilized the capital theory by investigating the usage of various capitals by parents of children with special needs in the United States, and the author claimed that cultural capital played a crucial role when parents campaigned for children with special needs. Specifically, she proposed 'the naming of the disability' as a cultural capital pertaining to their awareness and knowledge about disability, which represented parents' views when they sought assistance, acquired professional understandings, and navigated special schooling systems (Trainer, 2010).

In the framework of the present study, cultural capital and its usage arose in the following areas when immigrant parents discussed navigating the special education system in the United States for their children with ASD.

Language Barriers as Obstacles to Accumulation to Cultural Capital

Building on Bourdieu’s theory of cultural capitals (1978/1986), researchers developed and added new insights to cultural capital by defining language/linguistic capital as a subtype of cultural capital that contributes or interfere in the accumulation of cultural capital through social interactions (e.g., Lang, 1986; Yosso, 2005; Goldthorpe, 2007). For example, Goldthorpe (2007) argued that, based on Bourdieu's cultural capital theory, which emphasizes the social class differences between school personnel and parents and the ways in which these differences can obstruct effective communication and mutual understanding, children of the upper class have an advantage in their understanding of the educational environment, while parents from lower classes found the school environment hostile because of language barriers, which had led to less parents’ participation in school-based activities.

This study showed a similar problem of cultural capital utilization that immigrant parents who interacted with schools and service providers reported that the language barrier contributes to communication difficulties, despite that they have lived here in the United States over a period of time, which consequently, have weakened their efforts of parental empowerment. For example, 6 of 13 immigrant parents talked about a rising number of miscommunications that caused mental stress that occurred when they communicated with schools regarding the education plan of their children, and parents ascribed the increasing number of miscommunications to a shift in the way they communicate, from face-to-face meetings in the past to online meetings in the present, which compounded their difficulty communicating with school.

When the context of the Covid-19 pandemic cannot be ignored in this study, and when ongoing discussions about the advantages and disadvantages of online versus face-to-face instruction in K -12 education settings are considered, the findings of this study regarding the role linguistic capital plays in the interactions between parents and schools/service-providers in special education indicate that parents with language barriers require special attention.

Adaptation of Understandings to Disability

Resistant capital is one of the six sub-types of cultural wealth or capital that were defined by Yosso (2005). Resistant capital refers to the knowledge and skills that are nurtured via oppositional behavior that confronts inequity. In the context of the current study, resistant capital is expressed by the shift and adaptation of immigrant parents' understandings of disability, especially ASD.

According to the findings of research 1 (the systematic review), parental comprehension is the third most influential factor (4%). The qualitative findings of the second study indicated comparable relationships between parents' service selections and their opinions regarding ASD. Additionally, when immigrant parents discussed the evolution of their understanding of ASD, their narratives often suggested a paradigm shift from the medical model to the socially constructed one. For instance, parents who have stated that they believe ASD symptoms are transient and would fade as therapy progresses are more likely to choose "aggressive" interventions aimed at decreasing problematic behaviors. Later, when some of them discovered that ASD might be a set of lifelong qualities that do not disappear as their children age, their views about ASD and their service preferences and ratings for these services altered.

In summary, the paradigm shift, as exemplified by altering parental perspectives of ASD, is the intellectual and ideological leap from seeking medical care to living in the community as a right for their children with ASD. Furthermore, this study's findings imply that this paradigm change may be connected to the duration of the parent's stay in the United States, whether they have pursued specialized degrees in special education, whether or not they are involved in advocacy and the severity of the child's autism. However, because this was not a quantitative study, it was not feasible to evaluate correlations across factors; this is, therefore, a potential area for future research.

Parental Advocacy as Ways of Building up Cultural Capitals

Acquisition of cultural capital is difficult for culturally diverse parents because they are more comfortable using informal sources of information, through personalized connections and conversational language, whereas in the bureaucratized structure of the special education system, information is transmitted through formal channels (Kalyanpur & Harry, 1999). Therefore, under the context of this study, the building up of cultural capital could be harder to come by for immigrant parents who have not experienced the American public school system themselves. According to researchers (e.g., Koegel et al.; Nachsen, 2005), advocacy activities may result in positive results (e.g., empowerment and accumulation of knowledge) for parents, which enable them to maintain an improved quality of life. The finding of this study suggested that parent advocacy not only enables them to be more active in exploring the special education system but also enables them to assist other parents in the same situation, thereby facilitating the dissemination and transformation of the cultural capital (i.e., the understanding of special education and disability) of the entire parents' community.

In this study, 4 out of 13 immigrant parents in this study discussed their efforts and endeavors to advocate for disability communities on behalf of their children and others with special needs in their towns or school districts. According to these parents, these advocacy campaigns facilitate a greater understanding of ASD and disability rights in general.

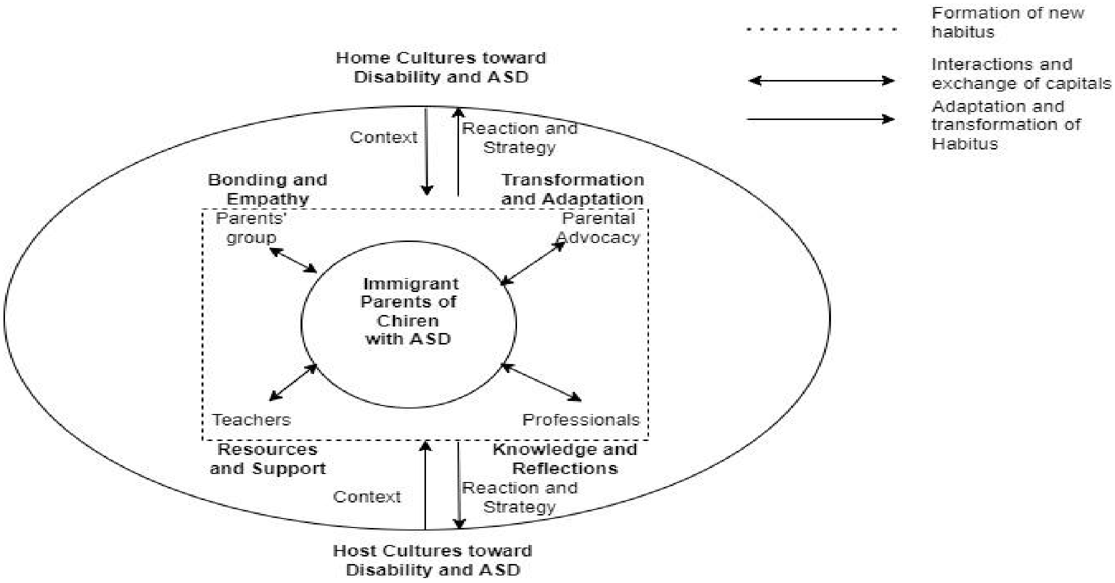
As Bowers (1984) suggested in his study about cultural capital and social competence, cultural capital acts as the knowledge and skills with which we negotiate our way in society as competent adults, immigrant parents utilized this knowledge to communicate and negotiate with service providers, such as schools, in order to obtain the best services for their children with ASD. Under this context, acquiring cultural capital about the special education system empowers parents to become effective partners in the educational decision–making process for their child. More importantly, as suggested by parents in the interview, knowing how school systems work has facilitated them helping other parents as advocates who have been through the system themselves as parents, and other parents would benefit from just observing how other parents negotiate their way through it. As parent 5 said during the interview, the parents' group is not always just about sharing resources; it also functions as a place for emotional support. According to her, the perspectives of immigrant parents who have negotiated their way with service providers for better services, including their choice of services and perceptions of disability, could be especially instructive for parents whose children have recently been diagnosed.

7.3 A Proposed Model for Identifying a Good Service

In this study, I analyze the emerging phenomenon of immigrant parents navigating the special education system in search of a "good service" for their children with ASD via the theoretical lens of a combination of habitus, social capital and cultural capital. Specifically, the theory of habitus gives a theoretical prism through which to examine, from the perspective of parents, what constitutes good service and how it develops and adapts. Next, the idea of social capital enables me to explore the interaction between immigrant parents and their social settings in their navigation for appropriate services for their children. Last, the theory of cultural capital offers a theoretical lens through which to examine the reflection on past knowledge and accumulation of knowledge in terms of 'good service' in the field of ASD intervention and services. Together, these three theory lenses allow me to observe how the capital and habits of immigrant parents of children with ASD are shaped and are shaping their perspectives on what constitutes a good service in special education through interactions with parties of interest that occurred within a social context defined by ecological system theory (Bronfenbrenner, 1979/1986).

Based on the analysis, I proposed a model for identifying a good service in the process of immigrant parents' navigation through the special education system in the United States, as indicated in Figure 6 below.

Figure 6 A proposed model for identifying a 'good service'



In this model, immigrant parents used social capital and accumulated cultural capital through their interactions with schoolteachers, professionals, parent advocates, and parent organizations. As a result of these interactions, immigrant parents adapted the perceptions that were ingrained in their home country and developed new habits regarding disability, ASD, and what constitutes a good service that is distinct from those of their home countries.

This concept implies that immigrant parents seeking "good services" for their children with ASD not only utilize social capital, cultural capital, and habitus in their interactions with their surroundings but that these interactions also contribute to the formation of their new habitus. Particularly, the understandings and interpretations of disability and ASD held by immigrant parents in their home culture are reconstructed and transformed throughout the process, combining with the dominant paradigm of understanding disability and autism in the host culture (i.e., the United States) to form a new habitus in their advocacy efforts for disability rights (including seeking for good services). In turn, this new habitus molded and enlarged their social and cultural capital, placing their subsequent advocacy actions inside a new cultural context. This model does not account for the effects of some individual factors, such as the severity of the child's ASD-related symptoms and the length of time immigrant parents have been in the United States.

Chapter VIII Conclusions

8.1 Evaluation of the Study

Through Bourdieu's theories of social capital, cultural capital, and habitus, this study aimed to add to an understanding of the subjective character of objective social institutions that immigrant parents must negotiate when advocating for their children with ASD in the United States. As Crotty (1998) proposed a researcher's ontological and epistemological positions are inherently linked because the construction of meaning is composed of portraying and interpreting reality, I believe that by utilizing this qualitative methodology within the interpretive-constructivist paradigms, the multiple-layered reality that builds the meaning of their experience based on their interpretation has been presented and described.

In the meantime, this study also includes limitations that arise both from my own positionality as both a mother of a child with ASD and a researcher and from procedural concerns that arose throughout the qualitative analysis, including the sample size and analytic process.

8.2 Limitations

Positionality as an Insider Researcher

As stated above under section 4.1.2, as an insider researcher, it is an uneasy task to investigate some of the personal experiences that I am aware of as potential methodological and ethical issues that are largely irrelevant to outsider researchers. In order to manage the challenges of locating myself in the space between, particularly those related to the insider position, I have reflected throughout the research process to consider the methodology and ethical challenges that may arise and plan carefully to address research questions.

Recruitment and Sampling

The current study only has 13 participants, which is a smaller number than the mean sample size of 31, which was suggested by Mason (2010) in an analysis of over 500 Ph.D. qualitative studies. Even though there is no universally agreed upon minimum number of participants required for a qualitative study, the number of participants is small. In addition to this, I recruited participants by snowballing and convenient sampling, and the results showed that the proportion of immigrant parents from Asian nations and regions (10) is much larger than the proportion of immigrant parents from other areas (3). It's possible that the recruiting process left out potential participants who may have contributed insightful new information. A further limitation of the present study relating to the sampling and recruitment method is that I relied on snowballing sampling; this meant that it was not possible to ensure complete anonymity to participants in every case, especially among these participants. In further studies, it would be beneficial to make an effort to investigate compassion in a variety of diverse demographics by using random sampling techniques.

Interpretative Phenological Analysis as Methodology

In the current study, I feel the use of the interpretative-constructivist paradigm/ontology for research purposes has been well justified. However, in an interpretative-constructivist paradigm, the findings might be presented and created by a few potential constructs, theories, and methodologies due to the study's dependence on the interview method. For instance, ethnographic approaches, discourse analysis, and narrative psychology methods might be useful alternative constructivist techniques for investigating and making meaning of events and acts in the lives of participants. As a result, it is extremely probable that the incorporation of these other methodologies would have resulted in models that explain immigrant parents' quest for good service for their children differently.

8.3 Procedural Measures to Ensure Standards of Quality, Trustworthiness and Rigor

As indicated in section 4.2.4, I employed a range of methodologies across all phases of this investigation to assure the legitimacy of the research findings by adhering to quality, credibility, and rigor requirements. Specifically, throughout the research, I have adhered to the recommendations of Charmaz (2014), Henwood and Pigeon (1992), Denscombe (2002), and Morrow (2005). Table 14 provides an overview of the procedures I've implemented to assure quality, credibility, and rigor.

Table 14 Procedure Measures for Quality of Research

Guidelines for Quality of Research	**Actions Taken**
Credibility: Denscombe (2002) suggested the credibility and quality of research	For study 1: The quality of all included studies was evaluated using the Standard Quality Assessment Criteria for Evaluating Primary

depend on the depth, scope, precision and validity of data.	Research Papers and the inter-rater assessment was conducted.
	For study 2: Three-step coding and analysis were carried out in depth in order to provide a rich and detailed account of parents’ experiences. Member checking will be carried out with each participant when the project is complete or any manuscript aiming to be published.
Closeness to the data: Charmaz (2014) and Henwood & Pigeon (1992) recommend that researchers stay close to the data by employing action-oriented coding and keeping codes brief and accurate.	For Study 1: This does not apply since it is secondary data because the purpose of Study 1's data is to complement the findings of Research 2 and assist in creating the interview process.
	For Study 2: I listened to the audio recording of each participant's interview as part of the three-step coding process in order to identify the participants' focus, clarify my comprehension, and verify the accuracy of the transcription. To create a model, constant comparison analysis was used to discover similarities and differences among emerging categories.
Reflexivity Morrow (2005) suggested the need to keep track of connections made	For Study 1: I went back to the findings of Study 1 and made constant comparisons with that of Study 2.

and constantly go back to the excerpts.	
	For study 2: I have used reflexivity by making memos throughout the research process to consider the methodology and ethical challenges that may arise and plan carefully to address research questions.

8.4 Implications for Research and Practice

In order for a culturally responsive policy/practice in special education to go from rhetoric to reality, immigrant parents of children with needs need to be more visible and supported. Understanding what constitutes a good service in the context of immigrant parents navigating the special education system in the United States has been enhanced by this study by offering a direct view into the experiences and perspectives of this growing population. Findings from this study may serve to inform the creation of resources that will more effectively support immigrant families in need of special education services for their children. I share the following suggestions, that I believe will assist such families and hence advance the field in the highlighted areas of research and practice.

8.4.1 Implications for Research

Because special education service outcomes are the result of interacting psychological and sociocultural processes, researchers interested in the interactions between immigrant parents and schools would do well to incorporate factors (variables) identified in this study into their explorations. Such variables would include national status (acknowledging that immigrant parents have often been conflated with other parent groups), duration of residence in the home culture (for immigrant parents), type and magnitude of disability, and disability-related perceptions of the host culture. In conclusion, special education researchers, particularly those whose research focuses on equity and accessibility concerns in this field, must design studies that account for the complexity of the phenomena of interest and the populations involved. In addition, multiple methodologies should be employed in order to evaluate distinct hypotheses appropriately. For instance, when conducting study 1 of this research, I discovered a small number of evidence-based quantitative studies examining the relationship between potential variables and parents' service choices, and an even smaller number of quantitative studies focusing specifically on under-representative parents, which suggests that researchers in the future should build on solid qualitative studies that would expand to larger numbers, which will help clarify the inferences that we can make from this largely invisible population. I acknowledge that more qualitative investigations that better clarify aforementioned factors may be necessary before moving toward larger-scale studies. Further, a mixture of qualitative and quantitative methodology may be most effective for understanding the experiences and perspectives of immigrant and other parent groups. Obviously, it is unreasonable to expect a single study to inform all about a particular population, but researchers should consider these concerns when they develop their research strategies.

8.4.2 Implications for Practice

To effectively address the unique needs of students and their families in special education, particularly for immigrant families, a multidimensional strategy is required, including personalized techniques for different stakeholders such as teachers, professionals, and parent groups. Schoolteachers should have cultural competence training about the communities that they serve, and learn to appreciate their students'' diverse backgrounds without relying on popular opinion or stereotypes. Professionals dedicated to supporting immigrant parents of children with special needs would benefit from administering intake questionnaires to better connect parents with peer support and advocate for evidence-based practices in supportive organizational settings. Parent support groups can improve their support networks by using peer matching, cultural competence courses, and community-building activities. Understanding and respecting cultural differences is critical to providing appropriate and effective special education services.

Schoolteachers could benefit from receiving extensive training on the history and concepts related to the populations that they support, which further develops their cultural competence . This training could include experiential narratives and scenarios like those highlighted in my second study, along with examples from common interactions with students and families. Recognizing the growing diversity of special education groups in the U.S. is critical, and teachers need to be prepared to meet the varied requirements of students from diverse linguistic, socioeconomic, racial, cultural, ethnic, and familial backgrounds. This suggested training would emphasize students' experiential and cultural diversity, encouraging teachers to respond to diversity without resorting to cultural stereotypes or other deficit ways of thinking. Teacher training might be structured throughout the year with a series of workshops. These workshops could include learning about the experiences of immigrant parents with children of special needs through constructed profile narratives, which could spark discussions about the importance of understanding community points of view.

Professionals (e.g., school psychologists and special education consultants) could benefit from conducting intake surveys (Attachment 5_Sample of in-take survey) for parents' help groups, asking about their children's types of disability, official diagnosis, and immigration status, including length of stay in the US. Example questions that could be included in the intake survey are:

- What are the primary challenges your child faces?
- What is your child's official diagnosis?
- How long have you and your child been in the US?
- What kind of support or resources have you found most helpful so far?

This information might aid specialists in matching parents with suitable peer families. Advocating for the use of evidence-based strategies in special education is critical. Professionals would do well to stay current on the newest research and approaches for efficiently meeting the requirements of different student populations, albeit this may a perennial issue for all teachers in the U.S. For professionals who support parent help groups: Consider using a similar intake survey described above to connect parents with peer families that share similar experiences. Such matching might be based on the children's diagnoses, symptoms, and immigration status, ensuring appropriate support and common understanding. Offering workshop resources to immigrant parent that highlight various culturally laden practices of schools to parents may help this vulnerable population to better navigate the special education system and effectively advocate for their children. Furthermore, cultivating a community that recognizes and respects cultural and experiential differences of all its residents is critical. Encouraging open discussions and activities that foster a supportive network among parents from all backgrounds could improve the effectiveness of parent aid groups as well as school educators and leaders.

Providing culturally sensitive special education services necessitates a thorough awareness of cultural concerns and the various needs of children and their families. By providing targeted training for teachers, adopting realistic measures for professionals, and developing supportive parent help groups, we can increase the effectiveness of special education programs and better support the varied student population. Understanding the complexities of cultural issues and avoiding broad generalizations are critical steps in this process.

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Appendix

Appendix 1 Table of Types and Findings of the Included Studies

Types of Studies	Authors	Country	Number of Participants (CALD/Total)	Quality Score	Findings Relating to Parents' Choice of Services
Mixed Methods					
1	Jashar et al., 2019	US	74/257	0.6 for the quantitative study and 0.8 for the qualitative study.	- Quantitative findings: Minority parents were less likely to report satisfaction with diagnostic services than non-minority parents ($p = 0.01$). - Qualitative findings: Positive communication between providers and parents affected parents' perception of care providers and their services.
2	Birkin et al., 2008	New Zealand	12/76	0.6 for the quantitative study and 0.75 for the qualitative study.	- Quantitative results: Families from minority ethnicities were less likely to participate in the service ($p = 0.0001$); one of the barriers to participation (mentioned by five respondents) was the wait time ($p < 0.01$). - Qualitative findings:

					Language barriers, parents’ beliefs about ASD, program pedagogy and parents’ pre-existing obligations from work/life were reported.
Quantitative Study					
3	Bilaver & Havlicek, 2019	US	354/1420	0.78	- Latino children with ASD were significantly less likely to have ever used school-based occupational therapy ($p < 0.01$) or physical therapy (PT) ($p < 0.001$). - Black children were 29 percentage points more likely to receive cognitive-based therapy compared with White children ($p = 0.03$). - The global race/ethnicity effect was significant for non-school-based PT ($p = 0.009$). - Parents’ beliefs about ASD (i.e., whether it can be changed) were statistically associated with the odds of receiving school-based ($p = 0.019$) and non-school-based services ($p = 0.019$). - Having private health insurance was significantly associated

					with lower odds of non-school-based PT service ($p = 0.034$). - Children whose parents had higher education backgrounds had significantly lower odds of receiving school services ($p < 0.001$).
4	McLeod & DiSabatino, 2019	US	354/1420	0.6	- Parents of older children were less likely to believe their child's condition is temporary than parents of younger children, and less likely to believe the symptom could be decreased with treatment ($p < 0.01$). - Parents with higher incomes were more likely to believe their child's condition could be prevented or decreased with treatment ($p < 0.01$).
5	Solgi et al., 2022	US	315/428	0.65	- Children whose parents expressed developmental concerns were shown to have a higher likelihood of being evaluated in early intervention compared to children whose parents did not express such concerns (66.9% vs. 45.2%; $p = 0.001$).

6	Zeleke et al., 2019	US	347/1715	0.75	- Minority parents were less likely to contact professionals about their concerns, and they waited longer to get their child diagnosed ($p = 0.006$). - Minority parents reported school services were more responsive than services provided outside schools ($p = 0.004$).
7	Zuckerman et al., 2015	US	352/2408	0.85	- Hispanic and Black non-Hispanic children were less likely to believe their child’s condition was lifelong ($p < 0.05$). - Parents who believed that their child's condition was lifelong rather than temporary were more likely to have a child who was using one or more psychotropic medications ($p = 0.026$).
Qualitative Study					
8	Chen et al., 2013	US	11/42	0.7	Asian parents with lower social and economic status expressed lower interest in accessing the genetic testing service.

9	Pondé & Rousseau, 2013	Canada	48/48	0.8	Mothers of older children may not agree with the psychiatric diagnosis.
10	Chlebowski et al., 2018	US	29/29	0.75	Factors negatively affecting service delivery: - Limited parents' knowledge of ASD. - Different perceptions between therapists and parents regarding parental participation in service. - Difference in the perceived culture of ASD. - Negative personal connection.
11	Fong et al., 2021	Canada	20/20	0.8	Barriers to accessing service: - Long service waiting time. - Language barriers. - Negative experience of interacting with professionals. - Local culture's attitude toward ASD. - Out-of-pocket cost. - Lack of detailed guide to services. - Stigma to ASD.
12	Fong et al., 2022	Canada	13/13	0.8	Barriers to accessing services:

					- Cultural values related to ASD (in the home country). - Stigma/discrimination associated with ASD. - Service inclusivity (culturally sensitive or not). - Isolation from the community.
13	Fox et al., 2017	UK	15/15	0.75	Barriers to accessing services: - Stigma associated with ASD. - The perceived home cultural attitudes toward ASD. - Parents' understanding of ASD.
14	Habib et al., 2017	Ireland	7/7	0.7	Barriers to accessing services: Cultural factors (home culture's attitudes toward disabilities).
15	Hubert, 2006	UK	30/30	0.9	Issues in relation to service provision: - Sufficient or accessible information about available services. - Poor communication between carers and service providers. - Language barriers.

					- Social isolation from the community in which they live. - Service charges which are not within their means to pay. - Lack of family support. - Poor health conditions of parents.
16	Huer et al., 2001	US	43/43	0.9	- Parents who have immigrated for a longer period of time are more receptive of and satisfied with the service. Barriers to accessing services: - Language barriers. - Lack of knowledge of the special education system.
17	Kang-Yi et al., 2018	US	13/13	0.75	Barriers to accessing services: - Prevailing community attitude toward ASD: discomfort, stigma, and discrimination. - Parents’ understandings of ASD.
18	Khanlou et al., 2015	Canada	27/27	0.8	Barriers to accessing services, from professionals' perspectives: - Language barrier.

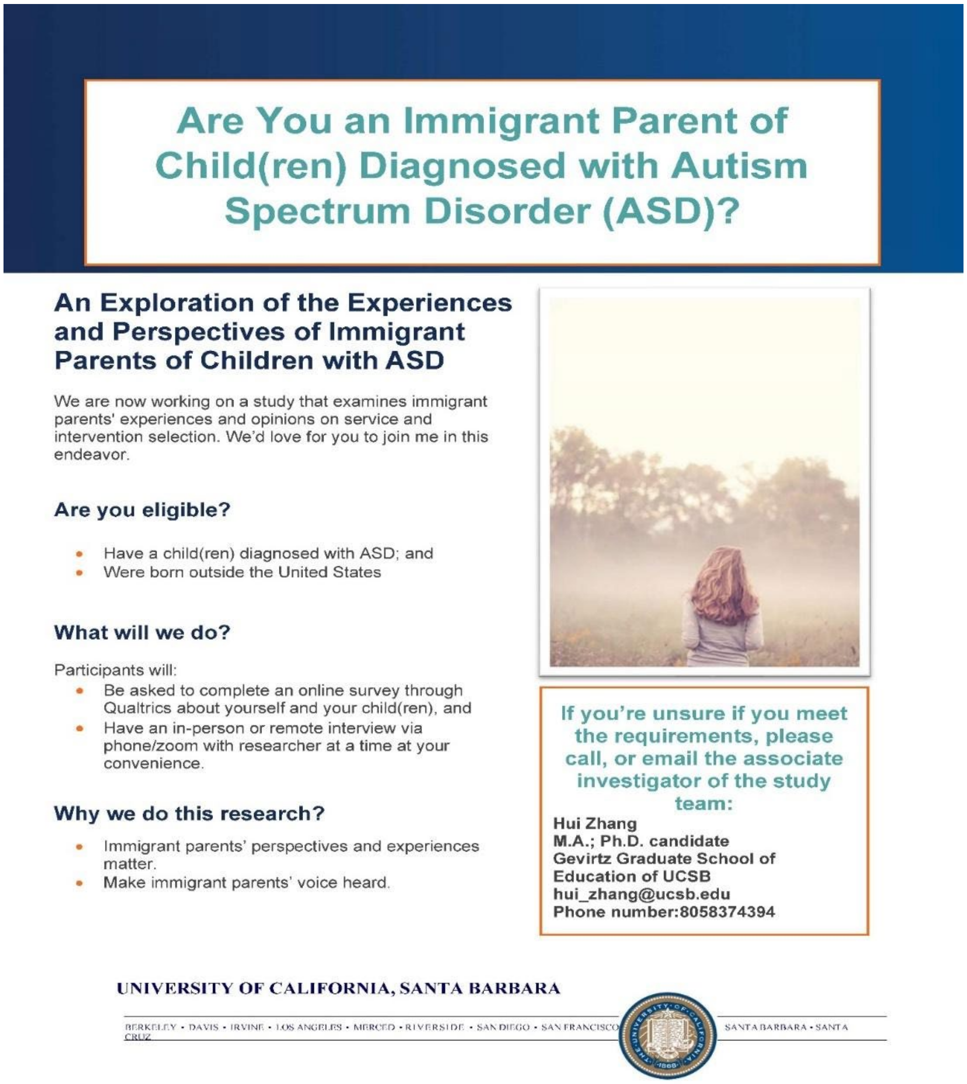
					- Lack of familiarity with medical language. - Complexity of service systems. - The perceived home culture's negative attitudes toward disabilities.
19	Kim & Dababnah, 2022	US	20/20	0.75	Barriers to accessing services, from professionals' perspectives: - The perceived home cultures. - Language barriers.
20	Kizildag et al., 2022	US	12/26	0.9	Concerns of participants in choosing services: - Cost and time spent (minimizing family burden). - Immigrant mothers emphasized the helpfulness of the logistical support provided by services.
21	Millau et al., 2018	Canada	45/45	0.75	- Immigrant parents preferred the prevailing treatment in their home countries. - African immigrant families are more likely to choose the traditional treatment than immigrant families from western

					European and Asian countries.
22	Montoya et al., 2022	US	9/9	0.7	Barriers to accessing services: - Language barriers. - Knowledge of the special education system.
23	Pearson et al., 2020	US	12/12	0.8	Factors that facilitate accessing service: - Partnership between the service provider and parents. - Knowledge of the special education system.
24	Perepa, 2014	UK	63/63	0.75	Factors reported: - The home culture's attitudes toward ASD. - Acculturation into the UK, especially regarding cultural attitudes toward disabilities. - Gender difference in choosing services for their child between fathers and mothers.
25	Pondé & Rousseau, 2013	Canada	35/35	0.8	Factors that facilitate accessing service: - Parents' understanding of ASD. - Informal supporting networks.

					- Parents’ educational background and income status. - Connections to cultural community organizations.
26	Ravindran & Myers, 2013	US, Canada, and Saudi Arabia	24/24	0.85	Factors reported: - Parents’ beliefs about ASD (causes, treatment). - The perceived host culture’s attitudes toward ASD. - The perceived home culture’s attitudes toward ASD.
27	Rivard et al., 2019	Canada	34/34	0.85	Barriers and facilitating factors: - Long waiting time to get service. - Being isolated from the community. - Parents’ knowledge of and attitude toward ASD.
28	Sakai et al., 2019	US	16/16	0.8	Factors reported: - Communication between service providers and parents. - Parents’ cultural beliefs about disabilities.
29	Shanmugarajah et al., 2022	Canada	8/8	0.7	Language barriers are reported as the major barrier to accessing services.

30	Stahmer et al., 2019	US	26/56	0.9	Facilitating factors reported: - Parental advocacy. - Support from family members. - Partnership with service providers. - Support from the community. - Support from other parents. Barriers reported: - Parents’ obligations in life and work. - Language barriers. - Lack of knowledge of ASD. - Stigma of ASD. - The complexity of the special education system - The insecurities arising from being an immigrant.
31	Xu et al., 2022	US	12/12	0.75	Community-based settings offer enhanced accessibility over clinic-only settings for intervention services.

Appendix 2 Recruitment Flyer



Are You an Immigrant Parent of Child(ren) Diagnosed with Autism Spectrum Disorder (ASD)?

An Exploration of the Experiences and Perspectives of Immigrant Parents of Children with ASD

We are now working on a study that examines immigrant parents' experiences and opinions on service and intervention selection. We'd love for you to join me in this endeavor.

Are you eligible?

- Have a child(ren) diagnosed with ASD; and
- Were born outside the United States

What will we do?

Participants will:
- Be asked to complete an online survey through Qualtrics about yourself and your child(ren), and
- Have an in-person or remote interview via phone/zoom with researcher at a time at your convenience.

Why we do this research?

- Immigrant parents' perspectives and experiences matter.
- Make immigrant parents' voice heard.

If you're unsure if you meet the requirements, please call, or email the associate investigator of the study team:

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Appendix 3 Consent Form

Protocol Number: 7-21-0754

Approved by the UCSB Human Subjects Committee for use thru: 11/17/2031

SUMMARY OF KEY INFORMATION:

You are invited to participate in a research study conducted by the researchers listed below. You may participate in this study if you are at least 18 years old and are first-generation immigrant parents of children with an autism spectrum disorder. Your participation is voluntary, which means you can choose whether you want to participate. You may withdraw at any time without penalty. If you decline to continue, any data gathered to that point may be used in data analysis. If you choose not to participate, there will be no loss of benefits to which you are entitled. Before you can make your decision, you will need to know what the study is about, the possible risks and benefits of being in this study, and what you will have to do in this study. If you have any questions at any time, please feel free to ask the researcher and the research team. If you decide to participate, you will be asked to sign this form.

PURPOSE:

You are being asked to participate in a research study. The purpose of the study is to understand the perspectives of immigrant parents of children with autism on what constitutes a good service based on their own experiences.

PROCEDURES:

If you decide to participate, we will conduct aphone call interview that will last around an hour, and the interview will be recorded by an audio recorder. Before the interview, you will be asked to fill out an online survey through Qualtrics with 14 questions aboutdemographic information of you and your children.

RISKS:

It is expected that participation in this study will provide you with no more than minimal risk or discomfort, which means that you should not experience it as any more troubling than your everyday daily life. However, there is always the chance that there are some unexpected risks. The only foreseeable risk is answering questions that could cause discomfort because they might remind you of unpleasant experiences. You do not have to answer any questions that you choose not to respond to.

BENEFITS:

There is no direct benefit to you anticipated from your participation in this study. However, your participation in this study will help improve the understanding of immigrant parents' perspectives of children with autism in the US. The study may result in information that will help stakeholders of inclusive education develop detailed guidance or a handbook aiming for better service to immigrant families of children with special needs.

CONFIDENTIALITY

Absolute confidentiality cannot be guaranteed, since research documents are not protected from subpoena. All identifiable information (e.g., name, date of birth, working office, etc.) collected in this study will be stripped of identifiers. A pseudonym will be used to identify participants; no actual names will be used. Your personal information will never be used in a publication. We will be reporting information on participants in average numbers rather than personal information. Material from the transcripts will be used for data analysis and in presentations of our findings without your additional informed consent. Interviews will be recorded upon the consent of the interviewee by an audio recorder and the interview will be transcribed. The recording of interviews will be only accessible to researchers of this project for analysis purposes only and recording tapes will be destroyed 6 months after this study.

COSTS/PAYMENT:

N/A

RIGHT TO REFUSE OR WITHDRAW:
You may refuse to participate and still receive any benefits you would receive if you were not in the study. You may change your mind about being in the study and quit after the study has started.
QUESTIONS:
If you have any questions about this research project or if you think you may have been injured as a result of your participation, please contact: Principal Investigator: Diana Arya darya@ucsb.edu Graduate student investigator: Hui Zhang hui_zhang@ucsb.edu If you have any questions regarding your rights and participation as a research subject, please contact the Human Subjects Committee at (805) 893-3807 or hsc@research.ucsb.edu. Or write to the University of California, Human Subjects Committee, Office of Research, Santa Barbara, CA 93106-2050 PARTICIPATION IN RESEARCH IS VOLUNTARY. YOUR SIGNATURE BELOW WILL INDICATE THAT YOU HAVE DECIDED TO PARTICIPATE AS A RESEARCH SUBJECT IN THE STUDY DESCRIBED ABOVE. YOU WILL BE GIVEN A SIGNED AND DATED COPY OF THIS FORM TO KEEP. Signature of Participant or Legal Representative:_________________________________ Date:_________ Time:____

Apppendix 4 Survey

Thank you for your participation in this study, which is designed to make visible the perspectives and experiences of parents who immigrated to the U.S. and have children with ASD. Your responses will help clarify the strengths, weaknesses and needs of U.S. educational systems for supporting families like yours. This survey involves 14 questions, most of which are multiple choice, and should not take more than 10 minutes. You participation is voluntary, and we really appreciate your input for this study.

Section I: About Children

1. Age of your child

Please specify your child's age_________

2. Gender of your child

- Female
- Male
- Other (specify)

3. Number of Child

How many children do you have?

- 1

- 2
- 3
- 4
- Other numbers(please specify：)

And your child(ren) with ASD this is your _____child (birth order).

4. Grade

What grade is your child? _________

5. Type of School

Where does your child go to school?

- Public school
- Private School
- Special institution
- Homeschooling

Others(specify)___________________

6. Inventory of service/intervention received

Please tick all that apply and specify those not on the list

At school:

Occupational Therapy ☐ Language Therapy ☐ Applied Behavior Therapy ☐

Social Skills Training ☐ Physical Therapy ☐ Sensory Integration Therapy ☐

Please specify is not listed above:

Outside School:

Occupational Therapy ☐ Provider: Language Therapy ☐ Provider:

Applied Behavior Therapy ☐ Provider: Social Skills Training ☐ Provider:

Physical Therapy ☐ Provider: Sensory Integration Therapy ☐ Provider:

Respite Service ☐ Provider:

Please specify is not listed above:

Section II: About Parents

7. **Age**

Which category below includes your age?

- 17 or younger
- 18-20
- 21-29
- 30-39
- 40-49
- 50-59
- 60 or older

8. **Gender**

What is your gender?

- Female
- Male
- Other (specify)

9. **Marital status**

Are you now married, widowed, divorced, separated, or never married?

- Married
- Widowed
- Divorced
- Separated
- Never married

10. **Education**

What is the highest level of school you have completed or the highest degree you have received?

- Less than a high school degree
- High school degree or equivalent (e.g., GED)
- Some college but no degree
- Associate degree
- Bachelor's degree
- Graduate degree

11. **Race and Cultural backgrounds**

- Are you of Hispanic, Latino or Spanish origin?
    1) No, not of Hispanic, Latino or Spanish origin
    2) Yes, Mexican, Mexican American, Chicano

    3) Yes, Puerto Rican
    4) Yes, Cuban
    5) Yes, other Hispanic, Latino or Spanish origin (Please specify)
- If not of Hispanic, how would you best describe your cultural or ethnic background? Select all that apply (National Center for Statistics Reporting Category, 2007).

  1) American Indian or Alaska Native

  2) Asian

  3) Black or African American

  4) Native Hawaiian or Other Pacific Islander

  5) White

  6) Two or more races

  7) Race and Ethnicity unknown

  Others(specify):

12. Year of Residence in the US:

_______Years

living in (name of the states)

13. Employment

Which of the following categories best describes your employment status?

- Employed, working 1-39 hours per week
- Used, working 40 or more hours per week
- Not employed, looking for work
- Not employed, NOT looking for a job
- Retired
- Disabled, not able to work

14. Annual Income

Which of the following categories best describes your family's yearly income status?

- 0-10,000
- 10,000-50,000
- 50,000- 100,000
- 100,000- 200,000
- 200,000-300,000

- 300,000-400,000
- 400,000-500,000
- 500,000-1,000,000
- 1,000,000 and above

Appendix 5 Interview Protocol

Experience with diagnose/service/intervention

Probe: Diagnose and reference (if diagnosed in the US)

- Could you please tell me what prompted you to become concerned about your child's development?
- Could you please elaborate on what you did after diagnosing?
- What reference did you get? And what did you think is the major reason for that reference?

Probe: If diagnosed abroad

- Where did you get the diagnose? Could you please describe the process?
- What happened after the diagnose?
- What kind of service or intervention did your child ever get? How did that work with your child?

Probe: applicable to all scenarios

- Could you please explain the intervention process to me? What did you think that is back then?
- What were your main concerns while deciding on the intervention approach and the agency with whom you are currently working?
- Did you ever try looking for intervention by yourself via friends or online? How and what did you find effective?
- What aspects do you think is important for early ASD intervention?
- Do you intend to continue the current interventions or change to new intervention in the future? Why?
- Is there anything you would rather do differently if you were given the chance to?

Experience with School Services

Probe: Choice of School

- Did your child ever attend schools (including preschool, kindergarten, daycare, etc) outside the US? if yes, could you please describe what it is like, for example do they provide any service to children with disabilities?
- Could you briefly describe the type of school service your child is now receiving?
- Is there a reason you choose this school?

Probe: Experience with School Service

- How is you child doing at the school?
- Do you have any concerns about the school services and what do you like most about their service?
- How would you describe the differences or commonalities between these services and interventions you mentioned earlier?
- What is you plan about your child as an adult graduating from K12 school education?

Appendix 6 Sample of in-take survey

Purpose: This survey aims to gather detailed information about the needs and backgrounds of families to better match you with appropriate peer support and resources.

Basic Information:

1. Parent/Guardian Name:
2. Child's Name:
3. Child's Age:
4. Contact Information (Phone/Email):

Child's Health and Education:

5. Primary Diagnosis: (e.g., Autism Spectrum Disorder, ADHD, etc.)
6. Please describe the primary symptoms or challenges your child faces.

Immigration Status and Background:

7. How long have you and your child been in the United States?
8. What is your family's primary language spoken at home?

9. Please describe any significant cultural or religious practices your family follows that might impact your child's education or care.

Educational and Support Needs:

10. What type of educational setting is your child currently in? (e.g., public school, private school, homeschool, etc.)
11. What types of support or resources have you found most helpful so far? (e.g., speech therapy, occupational therapy, counseling, etc.)
12. Are there any specific areas where you feel your child needs more support? (e.g., social skills, academic assistance, behavioral support, etc.)

Parent/Guardian Experience:

13. Have you experienced any challenges in accessing educational resources or support for your child? If so, please describe.
14. Are you currently part of any parent support groups or networks? If yes, please list them.
15. What type of support would you find most helpful from a parent support group? (e.g., peer matching, educational workshops, emotional support, etc.)

Additional Information:

16. Do you have any other children with special needs? If yes, please provide details.
17. Are there any other specific needs or concerns you would like to address in this survey?
18. Would you be interested in participating in cultural competence workshops or community-building activities?

Thank you for taking the time to complete this survey. Your responses will help us better match you with resources and peer support that meet your family's unique needs.