How Can We Enable Hmong Parents to Take Steps Towards Autism Identification?: Hmong Parents' Beliefs about Autism and Their Experiences in the Identification Process

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n vgby mn n vmn nn n fvtytrrdtn um m vr
vgvbvb vvbbbbb cv vy cd c cc

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Dedication

This dissertation is dedicated—

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To my brother, Yuepheng, who has inspired nearly every aspect of my education and doctoral research.

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Abstract

An early identification of autism spectrum disorder (ASD) is important for early access to supports and intervention services. Evidence suggests that age of identification may be particularly late for children from underserved, culturally and linguistically diverse (CLD) communities. Although parents play an important role in their child's receipt of an ASD identification, CLD parents may experience more challenges in the identification process, which likely better supports the needs of White, middle class, English-speaking families. Very little ASD research has focused on the Hmong community, a CLD group that is particularly vulnerable to inequities in ASD identification. Thus, I conducted a three-study dissertation that examines Hmong parents' beliefs about ASD and their experiences in the identification process to address the overarching question: *how can we enable Hmong parents to take steps towards an ASD identification?* To first gain a more thorough understanding of parents' experiences in the ASD identification process, Study 1 was a systematic review of barriers and facilitators to ASD identification reported by parents in the U.S. across qualitative and descriptive studies. In Study 2, I specifically examined Hmong parents' (N = 35) beliefs related to ASD (i.e., their beliefs about early identification, intervention and the causes of ASD) and their experiences in the identification process (i.e., the barriers and facilitators they encountered) using a survey tool I developed called the Parent Perceptions of Autism Spectrum Disorder survey (PP-ASD). Using the same participants and the PP-ASD, Study 3 examined the sources Hmong parents use to obtain information on ASD, as well as the extent to which they encounter and utilize ASD information presented in Hmong text and audio. These studies point to the importance of ensuring that Hmong parents have access to information on ASD and that healthcare and educational professionals be supported to serve as partners.

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Chapter 1: Introduction

1.1 Overview

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by unique social communication characteristics (i.e., in the areas of social-emotional reciprocity, nonverbal communication, and relationship management) and restricted repetitive behaviors (i.e., in the forms of stereotyped/repetitive behaviors, insistence on sameness, restricted interests, and unusual sensory behaviors; American Psychiatric Association, 2013). Individuals can be identified for ASD in two ways: (1) an educational eligibility (EE) and (2) a clinical/medical diagnosis (CD). An EE is regulated by the Individuals with Disabilities Education Act (IDEA) and is conducted by a multidisciplinary team following criteria from the Diagnostic and Statistical Manual of Mental Disorders-4 (DSM-4), wherein a student qualifies for services under ASD if they present social communication deficits generally before age three that adversely impacts their educational performance (IDEA, 2012). IDEA allows states to further modify eligibility criteria, and thus criteria and assessment processes vary by state. In contrast, a CD involves developmental screening and a comprehensive diagnostic evaluation conducted by a developmental pediatrician, child neurologist, child psychologist, or child psychiatrist (CDC, 2018). A CD of ASD is based on criteria from the DSM-5, which requires deficits in three areas of social communication and at least two areas of restricted, repetitive behavior (APA, 2013). Autistic[1] individuals can have an EE, CD, or both. For example, an individual may have a CD but not an EE if their educational performance is not adversely impacted. In this paper, the term "identification" is used when referring to both EE and CD.

[1] This dissertation uses identity-first language (e.g., autistic children) as opposed to person-first language (e.g., children with autism) in accordance with the American Psychological Association's (2021) inclusive language guidelines, which recommend usage of the language that an identity group prefers. Autistic individuals who have been able to have long indicated preference for identity-first language (e.g., Botha et al., 2021; Brown, 2011).

Studies indicate that ASD can be reliably identified by age two (Lord et al., 2006; Wetherby et al., 2004). More recently, Pierce et al. (2019) found that an ASD identification becomes stable as early as 14 months of age. In fact, only seven of 400 children initially identified with ASD were reclassified at age three as typically-developing, suggesting that there is a low chance a child who is previously identified with ASD would test as typically-developing over time. Despite the ability to identify ASD well before age two, the most recent data from the Autism and Developmental Disabilities Monitoring Network (ADDM), the largest ongoing ASD tracking system in the country, shows that the average age of identification in the U.S. is still after four (Maenner et al., 2021). Age of identification may be particularly late for children from underserved, culturally and linguistically diverse (CLD) communities. The term CLD in this paper follows the definition provided by Sullivan (2011), referring to racial/ethnic minority groups and groups with native languages other than English in the U.S. Older and/or smaller-scale studies (e.g., Magaña et al., 2013; Mandell et al., 2002; Shattuck et al., 2009; Sansosti et al., 2012) have indicated that CLD children spend a longer time in the evaluation process and are identified years later than Non-Latino White (NLW) children. ADDM data over the years, however, reveal that age of identification for Non-Latino-Black, Latino, and Asian/Pacific Islander children were comparable to NLW children. Furthermore, ASD prevalence among these racial/ethnic groups appear to have narrowed over time. ADDM data from 2014 revealed that ASD prevalence was higher for NLW children than Non-Latino-Black and Latino children (Baio et al., 2018). ADDM data from 2016 showed that ASD prevalence was similar among NLW, Non-Latino-Black and Asian/Pacific Islander children and was only lower for Latino children (Maenner et al., 2020). Most recently, 2018 data revealed that ASD prevalence was similar for all four racial/ethnic groups (Maenner et al., 2021).

Although ADDM data paint a positive picture of narrowing identification inequities, these findings must be considered in light of several limitations. ADDM data determines ASD identification by assessing medical and educational records as opposed to conducting comprehensive evaluations. Additionally, the ADDM network consists of 11 sites that are not representative of their respective states or the population of the U.S. As the geographic area of sites change over surveillance years, temporal trends in ADDM data (e.g., trends in age of first identification, trends in prevalence) may actually reflect changes in sample. Furthermore, looking at ADDM data nationally may provide an inaccurate picture of identification inequities within states as state prevalence rates and ages of identification vary. For example, although 2016 data showed similar ASD prevalence between NLW and Non-Latino-Black children nationally, significant group differences were found in Arkansas and New Jersey sites. Thus, ADDM findings should not serve as evidence to quell efforts to improve identification inequities but instead serve as a push for more complex examination of identification outcomes. For example, when source of ASD records (education records or health records) were examined from 2018 data, Esler et al. (2022) found that Black, Asian, and Latino children were more likely than NLW children to only have education records of ASD; and interestingly, children who only have education records of ASD were identified approximately two years later than children who only have health records of ASD and children who have both records of ASD.

In summary, not only is ASD identified later than what is possible, but there is evidence that racial inequities in age of identification may be present. Specifically, CLD children may be identified later than NLW children.

1.2 Consequences of Delayed ASD Identification

Delayed ASD identification is problematic for several reasons. First, an ASD identification provides important social-emotional supports that are crucial in facilitating the acceptance of and adaptation to ASD and for improving mental health for autistic individuals and their families. These supports include validation of long-held observations and concerns, answers to long-awaited questions, alleviation of guilt and self-blame, connections to the autistic community, and perhaps also a new social identity (Anderson-Chavarria, 2021; Cooper et al., 2017; Watson et al., 2008). Thus, delayed ASD identification may mean delayed receipt of the necessary supports that set individuals and families on a trajectory towards sense-making and resilience.

Additionally, an ASD identification is often needed in order to access services. An EE provides access to Part C early intervention services for children birth through age 3 and Part B special education services for children age 3 through 21 through IDEA. Although IDEA allows children from birth through age 9 to receive special education services under the nonspecific developmental delay (DD) eligibility, recommendations from the Division for Early Childhood (2009) state that a DD eligibility should not preclude or simply be used to avoid an appropriate disability-specific eligibility. Specifically, not identifying low incidence disabilities such as ASD may result in the loss of appropriate services, access to appropriately qualified providers, and funding for services that are earmarked specifically for ASD. Whereas an EE provides access to services in school, a CD provides access to services outside of school such as Early Intensive Developmental and Behavioral Intervention (EIDBI) and other waiver-based services and supports. A CD also guarantees some extent of insurance coverage for ASD services in all 50 states and Washington D.C., thereby enabling families to utilize services that they otherwise may not be able to afford (National Conference of State Legislatures, 2021).

Receiving services early is crucial as decades of research have demonstrated that intensive intervention during the first several years of life when brain development is most amenable to intervention (Knickmeyer et al., 2008; Markant & Thomas, 2013) can improve long-term outcomes for autistic individuals (e.g., Wetherby & Woods, 2006; Dawson et al., 2010; Dawson et al., 2012; Estes et. al., 2015; Landa, 2018; Reichow, 2012; Wetherby et al., 2018; Zwaigenbaum et al., 2015). As an ASD identification is often needed to access early and targeted intervention, delayed ASD identification can mean delayed intervention. Delayed intervention can position children to require longer, more intensive intervention, compromise outcomes, negatively impact quality of life, and significantly compound costs of lifelong supports, generally estimated at $1.4 million per individual with ASD in the U.S. (Buescher et al., 2014; Gourdine et al., 2011).

Given the provisions of an ASD identification, racial inequities in age of identification not only mean that CLD children and their families start the adaptation and sense-making process later than NLW children and their families but also that CLD children may miss opportunities to receive intervention during the most critical period of brain development. Efforts to promote and improve ASD identification, particularly for CLD children, are warranted.

1.3 Parents as Key Stakeholders

Parents are especially apt to support early ASD identification. They are often the first to notice and raise concerns about their child's development and often do so prior to age two, matching the age at which ASD can be reliably identified (Chawarska et al., 2007; Sansosti et al., 2012; Wong et al., 2017). Moreover, parents' concerns are generally indicative of a diagnosis, regardless of parent education level, socioeconomic status, and child-rearing experiences (Glascoe, 1999; Glascoe & Marks, 2011). Parents are also often the ones to navigate their child's identification process and play key roles. Tasks such as learning about ASD, retrieving accurate information, finding providers, scheduling and attending appointments, contributing information to assist with evaluations, completing paperwork, and securing child care generally fall on parents. Thus, enabling parents to take proactive steps towards identification at the onset of their concerns can significantly support the early identification of ASD. Examining parents' experiences in the identification process may inform ways parents can be supported to do so.

1.4 The Identification Process

In this study, the identification process is defined as starting when concerns about a child's development are first recognized, including screening, referrals, and evaluations, and ending with the receipt of an EE or CD of ASD. Receiving an ASD identification involves first recognizing concerns in a child's development. Concerns often come from parents but can also come from friends and family, healthcare providers, educators, other service providers, or positive results on an ASD screener such as the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F). A comprehensive evaluation typically follows; in general, evaluations conducted in schools with a multidisciplinary team result in an EE, while evaluations conducted in healthcare settings with medical providers result in a CD. The evaluation results determine the kinds of services and supports an individual and their family are eligible to receive.

Today, CLD parents are operating in an identification process that likely better supports White, middle-class, English-speaking families. The M-CHAT/F has lower specificity and positive predictive value in Black, Asian, and multiracial children and children with non-English exposure (Guthrie et al., 2019). Pediatric providers are also less comfortable and less likely to screen for ASD with non-English-speaking families (Zuckerman et al., 2013). Together, these findings suggest that CLD children are less likely to screen positive for ASD and that CLD families may have less opportunities to engage with providers about ASD. Additionally, commonly-disseminated early signs of ASD (e.g., lack of eye contact, lack of pointing, and language delays) emphasize Western cultural ideas of typical development (Ennis-Cole et al., 2013). This means “classic” symptoms of ASD may not be recognized by other cultural groups as indicative of a disability, let alone ASD (Donohue et al., 2019). Furthermore, healthcare providers are disproportionately White (LeLacheur et al., 2015), which can mean that CLD parents encounter additional challenges to identification such as cultural disconnect, language barriers, and practitioner bias. Finally, information on ASD in languages other than English is limited, which can mean that CLD parents with limited English proficiency are disadvantaged recipients of ASD information (Sakai et al., 2019; Stahmer et al., 2019). These conditions likely make it more difficult for CLD parents to be able to take steps towards an ASD identification.

Not surprisingly, a number of studies show that CLD parents experience inequities throughout the identification process. Constantino et al. (2020) found that Black parents’ concerns about their child’s development were dismissed by providers for several years. Christensen et al. (2018) and Valicenti-McDermott et al. (2012) found that children of color and children of foreign-born mothers receive fewer and later ASD evaluations. Similarly, Zeleke et al. (2019) found that significantly less CLD parents reported receiving ASD screenings and evaluations than NLW parents. This study also found that CLD parents were less satisfied than NLW parents with the identification services they received from both healthcare and educational systems. Altogether, these findings call for more research intentionally focused on understanding and improving CLD parents’ experiences in the identification process.

1.5 The Hmong Community

One CLD community that has received very little attention in ASD research is the Hmong community— a Southeast Asian refugee group with a U.S. population of approximately 310,000 and one of the fastest-growing ethnic groups in the U.S. The first Hmong families arrived in the U.S. in 1975 after Laos fell to communist forces during the Vietnam War. Over 30,000 Hmong soldiers, many of them boys as young as 10, were recruited by the U.S. to fight in what is termed the Secret War, where their death rate was 10 times that of American soldiers in Vietnam. Declared enemies of the state in 1973 by Lao communist forces for their participation in the war, an estimated 150,000 fled Laos to escape persecution, death, and internment camps. Many found their way to refugee camps in Thailand before being allowed entry into the U.S. (Minnesota Historical Society, n.d.; Public Broadcast Station, n.d.). A second wave of approximately 15,000 Hmong refugees arrived in the U.S. in 2004 after the closing of Wat Thamkrabok, a Buddhist temple compound that housed Hmong refugees who did not want to relocate to another country post-war.

In comparison to the general U.S. population, the Hmong community is more likely to be English language learners, to live in poverty, to rely on public assistance programs, to have lower educational attainment, and to have public versus private health insurance (American Community Survey, 2017). Such factors may mean that Hmong children are particularly vulnerable to inequities in identification, making it especially necessary that we understand how to support Hmong parents to take steps towards an ASD identification. Looking at Hmong parents' experiences in the identification process can inform ways to do so. To date, only a handful of published studies have examined ASD in the Hmong community (e.g., Bogenschutz, 2014; Estrem & Zhang, 2010, Minnesota Department of Health, 2014). As a Hmong graduate student and sibling of a brother on the spectrum, I am uniquely positioned to contribute to this research gap. My educational training here at the University of Minnesota is particularly advantageous as a quarter of the U.S. Hmong population (82,000) resides in Minnesota, with the Twin Cities serving as home to the largest Hmong community in the nation.

1.6 Program of Research

In summary, an early ASD identification is important for early access to supports and intervention services. Evidence suggests that CLD children are more likely to receive late ASD identifications. Although parents can play crucial roles in getting their child identified, the identification process may present more challenges for CLD parents, hindering steps towards an ASD identification. Looking to CLD parents' experiences in the identification process may inform ways to help parents move towards identification. Very little ASD research has focused on the Hmong community, a CLD group that is particularly vulnerable to inequities in ASD identification. Thus, I conducted a three-study dissertation that examines Hmong parents' beliefs about ASD and their experiences in the identification process to address the overarching question: *how can we enable Hmong parents to take steps towards an ASD identification?*

1.6.1 Study 1: Parent-Reported Barriers and Facilitators to Autism Identification: A Systematic Review of Qualitative and Descriptive Studies

To first gain a more thorough understanding of parents' experiences in the ASD identification process, Study 1 is a systematic review of barriers and facilitators to ASD identification (both EE and CD) reported by parents in the U.S. across qualitative and descriptive studies. As my dissertation focuses on parents' reports of the identification process, I was curious how factors *reported* by parents to expedite or impede ASD identification compared to factors *statistically-identified* from quantitative/correlational studies to predict age of identification. Finally, as the larger objective of my dissertation is to focus on Hmong parents, I wanted to know how representative the current literature on parents' experiences in the identification process is. Thus, five research questions guided this review:

1. What do parents report *prevent* their ability or willingness to move towards an ASD identification for their child?;
2. What do parents report *promote* their ability or willingness to move towards an ASD identification for their child?;

3. Which parent-reported barriers and facilitators overlap with factors associated with age of identification found in Daniels and Mandell (2014; a review of correlational studies examining predictors of age of identification)?;
4. What are the demographic characteristics of the parents represented in this literature?; and
5. What are the methodological trends of this body of literature?

This review served as the foundation of my dissertation. The barriers and facilitators found in this review informed, in large, the barriers and facilitators that I subsequently examined with Hmong parents in Study 2. One central theme from this review was the importance of ensuring that parents, particularly CLD parents, have access to information on ASD and identification; this theme formed the rationale for Study 3. The findings from this review were also used to develop the Parent Perceptions of Autism Spectrum Disorder (PP-ASD) survey, a retrospective parent-report survey that was used in Studies 2 and 3. The PP-ASD gathers (1) parents' knowledge and beliefs surrounding ASD (i.e., their beliefs about early identification, intervention, and the causes of ASD), (2) the barriers and facilitators they encounter in the identification process, and (3) the sources parents use to access information on ASD. The PP-ASD was created on Qualtrics ® using survey guidelines from Halaydna and Rodriguez (2013) and Dillman et al. (2014). It was piloted with a convenience sample of parents of autistic children from a university research registry (*N* = 114) and was recently used with a community sample in Chaxiong (2020; *N* = 205). (The PP-ASD can be viewed at https://z.umn.edu/Chaxiong_PP-ASD.)

1.6.2 Study 2: Hmong Parents' Beliefs About Autism and Their Experiences in the Identification Process

The literature suggests that the course of action parents take— or are able to take— towards an identification may in part be influenced by their identification experiences and their beliefs/knowledge related to ASD going into the identification process. As described previously, little is known of Hmong parents' ASD beliefs and identification experiences. This information may help inform ways to enable Hmong parents to take steps towards an ASD identification. Specifically, a better understanding of Hmong parents' knowledge and beliefs about early identification, intervention, and the causes of ASD may shed light on why Hmong parents do or do not seek an ASD identification. Secondly, identifying barriers and facilitators that are likely to predict age of identification can indicate problem areas and supportive factors that can be bolstered to make it easier for Hmong parents to move through the identification process. In Study 2, the PP-ASD was used to gather this information from 35 Hmong parents of autistic children. This study addressed three research questions:

1. What are Hmong parents' beliefs about early identification, intervention, and the causes of ASD?;
2. What barriers and facilitators do Hmong parents encounter during the identification process?; and
3. What are potential predictors of age of identification for Hmong children that may be worthy of investigation in future studies?

1.6.3 Study 3: A Preliminary Examination of the Information Sources Hmong Parents Use to Learn About Autism

Ensuring that parents, especially parents from CLD communities, have adequate access to information on ASD remains a challenge (Crais et al., 2020; Sakai et al., 2019; Stahmer et al., 2019). Studies that have examined the sources parents turn to for information on ASD have predominantly focused on White, middle-class, English-speaking participants or have not provided information on cultural and linguistic diversity. Lack of knowledge surrounding the information-seeking behaviors of CLD parents is problematic as decisions to seek ASD identification and intervention services are heavily influenced by what parents know and the information sources they use (Frame & Casey 2019; MDH, 2014; Pearson et al., 2018; Wong et al., 2017). To date, no published studies have examined the information-seeking behaviors of Hmong parents as it pertains to ASD. Given the Hmong community's unique combination of socioeconomic, cultural, and linguistic circumstances, this research is particularly warranted. Using participants from Study 2 and data from the PP-ASD, this study addressed three research questions:

1. What sources do Hmong parents use to obtain information on ASD?;
2. Does the number of information sources Hmong parents report using predict age of ASD identification?; and
3. What is the extent to which Hmong parents encounter and utilize ASD information presented in Hmong text and audio?

Chapter 2: Parent-Reported Barriers and Facilitators to Autism Identification: A Systematic Review of Qualitative and Descriptive Studies

2.1 Introduction

In addition to providing validation, a starting place for seeking answers, an identity, and connection to the autistic community, an identification of autism spectrum disorder (ASD) can open the doors to a world of supports and intervention services such as special education, speech therapy, occupational therapy, and behavioral intervention. Although receiving services at any time during development is beneficial, these services may make the most impact in the first several years of life when brain development is most robust and amenable to intervention (Knickmeyer et al., 2008; Markant & Thomas, 2013). Decades of research have demonstrated that early and intensive intervention can improve long-term outcomes for autistic individuals (e.g., Wetherby & Woods, 2006; Dawson et al., 2010; Dawson et al., 2012; Estes et. al., 2015; Landa, 2018; Reichow, 2012; Wetherby et al., 2018; Zwaigenbaum et al., 2015). Receipt of services, however, most often relies on receipt of an ASD identification.

Individuals can be identified for ASD in two ways: (1) an educational eligibility (EE) and (2) a clinical/medical diagnosis (CD). An EE is regulated by the Individuals with Disabilities Education Act (IDEA) and is conducted by a multidisciplinary team to determine an individual's eligibility to receive special education services. An EE of ASD follows criteria from the Diagnostic and Statistical Manual of Mental Disorders-4 (DSM-4), wherein a student qualifies for services under ASD if they present social communication deficits generally before age three that adversely impacts their educational performance (IDEA, 2012). IDEA allows states to further modify eligibility criteria, and thus criteria and assessment processes vary by state.

In contrast, a CD involves developmental screening and a comprehensive diagnostic evaluation conducted by a developmental pediatrician, child neurologist, child psychologist, or child psychiatrist (CDC, 2018). A CD of ASD is based on criteria from the DSM-5, which requires deficits in three areas of social communication (i.e., social-emotional reciprocity, nonverbal communication, and relationship management) and at least two areas of restricted, repetitive behavior (i.e., stereotyped/repetitive behaviors, insistence on sameness, restricted interests, and unusual sensory behaviors; American Psychiatric Association, 2013). Whereas an EE provides access to services in school, a CD provides access to services outside of school such as Early Intensive Developmental and Behavioral Intervention (EIDBI) and other waiver-based services and supports. A CD also guarantees some extent of insurance coverage for ASD services in all 50 states and Washington D.C. (National Conference of State Legislatures, 2021).

Autistic individuals can have an EE, CD, or both. For example, an individual may have a CD but not an EE if their educational performance is not adversely impacted. In this paper, the term "identification" is used when referring to both EE and CD. Although both types of ASD identification involve different systems and pathways to identification, follow different identification criteria, and provide access to different benefits and services, research has either focused on the experiences of obtaining a CD or has not distinguished between the two identifications, often using the term "diagnosis" broadly. Given the potential of early intervention services and their reliance on an early ASD identification, understanding the factors that delay and accelerate age of both identifications is critical.

Daniels and Mandell (2014) conducted an international systematic review of factors associated with age of diagnosis broadly. They found that greater symptom severity, higher socioeconomic status, and greater parental concerns were consistently associated with earlier diagnosis. Other parent-related factors associated with earlier diagnosis included showing concerns about social skills development and atypical behavior and having interactions with health and educational systems prior to diagnosis.

Children who (a) received early intervention, (b) were referred from early intervention programs as opposed to physicians' offices, schools, or parents or (c) were diagnosed in non-school settings like a hospital or specialty center were also associated with earlier diagnosis. Conversely, the authors found that presenting with comorbid health conditions, receiving a prior diagnosis other than ASD, and visiting a greater number of specialists and physicians were associated with later age of diagnosis. Children of immigrant mothers, children whose deliveries were paid for by Medicaid, and children of parents who attributed their condition to non-ASD behavioral difficulties or behavioral problems (e.g., child being stubborn, child having a difficult personality) were also associated with later diagnosis. Although age of diagnosis differed significantly by geographic region; the characteristics that explain these differences were unclear. Finally, cognitive ability, sex, parental age, birth order, having other children with ASD, and race or ethnicity showed either mixed or no relations to age of diagnosis. Based on these findings, Daniels et al. (2014) concluded that ASD diagnosis was potentially being driven by factors other than the clinical presentation of ASD and called for more "fine-grained analysis of factors that impede or expedite age at diagnosis" (p. 593).

A deeper understanding of such factors may be achieved by examining qualitative and descriptive studies. Daniels et al. (2014) examined quantitative, correlational data to identify factors that explain age of diagnosis; what qualitative and descriptive studies reveal about potential factors that affect age of identification remains a research gap. Qualitative studies tell us "what is happening?" and "why or how it is happening?" (Shavelson & Towne, 2002, p. 99). They center people and their lived experiences versus relations between variables. Qualitative approaches are also particularly conducive for examining the experiences of underserved communities, and thus a review of qualitative studies can reveal experiences that are not prominent in quantitative studies (Creswell, 2007). For these reasons, qualitative studies are apt to contribute rich, meaningful data that can spark subsequent research directions or clarify and supplement quantitative research findings (Brantlinger et al., 2005; McCrudden et al., 2019). Alignment in findings produced by both methods of inquiry would further strengthen and affirm our current understanding of a phenomenon.

2.1.1 Parent Experiences

A qualitative examination of parent experiences in the ASD identification process may be particularly helpful in improving our understanding of factors that potentially impact age of identification as parents often play crucial and active roles in their child’s identification process. Parents are often the ones to notice and raise concerns about their child’s development and are generally responsible for identifying providers, scheduling appointments, consenting to evaluation, and contributing information to assist with evaluation. Other logistical responsibilities such as retrieving accurate information, completing paperwork, making time to attend appointments, getting their child to and from appointments, and securing child care also fall heavily on parents. Given that parent-related factors such as education level, income, and greater parental concern were reported in Daniels et al. (2014) to predict age of diagnosis, a review directly examining what parents *report* to impede or facilitate ASD identification would present an important perspective for improving age of identification.

2.1.2 Purpose

The primary goals of this review were to examine parent-reported barriers and facilitators to ASD identification (both EE and CD) across qualitative and descriptive studies conducted in the U.S. and how they compare with factors reported in Daniels et al. (2014). To determine the generality and rigor of these findings, a secondary goal was to examine participant characteristics and the methodological trends of this body of literature. Five questions guide this review:

1. What do parents report *prevent* their ability or willingness to move towards an ASD identification for their child?;
2. What do parents report *promote* their ability or willingness to move towards an ASD identification for their child?;
3. Which parent-reported barriers and facilitators overlap with factors associated with age of identification found in Daniels et al. (2014)?;
4. What are the demographic characteristics of the parents represented in this literature?; and
5. What are the methodological trends of this body of literature?

This review uses a pragmatic interpretive framework (Creswell & Poth, 2018). That is, I intend for the findings to practically inform problem areas in the identification process that need to be addressed as well as supportive factors that can be bolstered to help parents move towards an ASD identification for their child. The identification process is defined as starting when concerns about a child's development are first identified, including screening, referrals, and evaluations, and ending with the receipt of an EE or CD of ASD. The term "professionals" is used to refer to both healthcare (e.g., pediatricians, family practice physicians, pediatric nurses, pediatric physician assistants, residents, psychologists, psychiatrists, and other ASD specialists) and school (e.g., general education teachers, special education teachers, paraprofessionals, school psychologists, principals, social workers/service coordinators) professionals involved in the ASD identification process. To my knowledge, there has not been a systematic review of parent-reported barriers and facilitators to ASD identification in the U.S.

2.2 Method

2.2.1 Researcher Description

I identify as a Southeast Asian doctoral student in special education at the University of Minnesota and have familial experience with the ASD identification process. To ensure a balanced outlook in conducting this review, I familiarized myself with the perspectives of professionals through (a) observing and training in conducting clinical evaluations, (b) attending seminars on current issues in ASD identification, and (c) reviewing the research on best identification practices.

2.2.2 Study Selection

Articles in this review were identified from Education Source, ERIC, Ovid, and PsycINFO in October of 2021 using the keywords and roots (asd OR autis*) AND (perception* OR attitude* OR belief* OR perspective* OR experience*) AND (parent* OR famil* OR mother* OR mom* OR father* OR dad*) AND (diagnosis OR assessment OR identification OR evaluation OR screening). This operation returned a total of 5,016 articles.

Studies were included if they were peer-reviewed, written in English, conducted in the U.S., and had as a research aim to examine parent experiences in the ASD identification process and/or included an interview/survey item that specifically asked about this experience. Studies that did not explicitly examine parent experiences in the identification process as described above were excluded even if parents ultimately shared their identification experiences (e.g., parents shared what it was like to get their child identified in a study that broadly examined stressors related to raising a child with ASD). It was determined that when neither the research question nor interview/survey items explicitly ask about parent experiences in the identification process, the sharing of these experiences would be by chance. To maintain a systematic study selection process, these studies were excluded. Additionally, exclusively correlational studies, case studies, and studies that specifically focused on the experiences of parents of children with comorbid health conditions (e.g., children with ASD and hearing impairments; Wiley et al., 2014) were excluded.

To identify studies meeting criteria, search filters on each database were set to include only peer-reviewed, English language articles. After duplicate articles were eliminated, a total of 3,475 articles were screened for relevance by title and abstract for a remaining total of 24 articles. The majority of excluded studies either did not examine parent experiences in the identification process specifically or were international studies. After full-text review, a total of 17 articles met inclusion criteria. A hand search of the references identified an additional article for a total of 18 articles (13 qualitative studies, two descriptive survey studies, and three mixed-methods studies). (See Figure 1 for PRISMA flowchart.)

2.2.3 Coding Procedures

A coding spreadsheet was iteratively developed on Google Spreadsheet to extract information on (a) study methods, (b) participants, and (c) parent-reported barriers and facilitators to obtaining an ASD identification. Method items included study design (e.g., qualitative, descriptive, mixed methods), study purpose, research questions, sampling method (e.g., snowball, convenience, purposive, clinical, registry), restrictions on length of recall, data collection methods or instruments (e.g., interview, focus group, survey), and method of analysis (e.g., thematic, narrative, grounded theory). Participant items included number of participants, number of male and female caregivers, race or ethnicity, geographic location, age, annual income, education level, years in the U.S., language(s) of study materials other than English, age of child, age of identification, and type of ASD identification (i.e., EE, CD, both). Midway into coding, several participant items were dropped (i.e., years in the U.S., age of child, age of identification, language(s) of study materials other than English) because of low applicability or a general trend of missing or unclear descriptions across studies. To capture parent-reported barriers and facilitators from qualitative studies, direct quotes or paraphrases of parent experiences in the identification process were recorded. To capture parent-reported barriers and facilitators from survey studies, survey items that described barriers and facilitators were recorded verbatim. No coding categories for parent-reported barriers and facilitators were developed a priori.

2.2.4 Analysis

Myself and a second coder independently coded each article for reliability purposes. As extraction of barriers and facilitators to diagnosis were open-ended and could be influenced by coder bias (Paterson et al., 2001), a series of coding meetings were dedicated to analyzing these extractions. The first coding meetings were used to determine whether the notes recorded by each coder indeed described barriers or facilitators to ASD identification. Notes describing barriers and facilitators unrelated to the identification process (e.g., obtaining intervention services) were excluded. Relevant notes were then separated into two columns on the coding spreadsheet based on whether they described barriers or facilitators to identification. Any discrepancies in notes were resolved through consensus after revisiting the respective studies. This was done to ensure that no barriers or facilitators were mistakenly recorded.

Next, several coding meetings were held to derive individual barriers and facilitators from the notes recorded using the constant comparative method (Glaser, 1965). This process entailed going note by note to compile as many unique columns of barriers and facilitators as possible on the coding spreadsheet. Notes that expressed similar sentiments were compiled into the same column (creating one unique barrier or facilitator) and notes that revealed a new sentiment started a new column (creating an additional barrier or facilitator). For example, notes describing professionals' dismissal of parent concerns were grouped together as one barrier; notes describing how parents felt challenged or undermined by professionals expressed a slightly different idea and thus started a second barrier. This process of comparing notes— grouping like-minded notes into the same column and creating new columns for different-minded notes— led to an exhaustive list of barriers and facilitators. Any uncertainty about how to group notes at this point were resolved by revisiting their respective studies. Each barrier and facilitator was then reevaluated in a second coding pass to ensure they expressed a discrete idea and were either collapsed or further disaggregated accordingly. Finally, a third coding pass was conducted to derive overarching themes that encapsulated all the barriers and facilitators.

2.3 Results

Table 1 describes the 18 studies included in this review with an overview of their methodology and participant descriptions. Studies are referred to as S*n*, where *n* refers to the order a study appears in Table 1.

2.3.1 Parent-Reported Barriers and Facilitators

Table 2 summarizes factors parents report prevented their ability or willingness to move towards an ASD identification for their child. Thirty-three barriers were identified across the 18 studies, revealing eight distinct themes: (1) limited knowledge, (2) dismissal of parent concerns, (3) challenging conditions of the identification process, (4) shortcomings of screening and diagnostic tools/procedures, (5) negative professional-parent interactions, (6) language barriers, (7) limited personal/family resources, and (8) legal barriers. Factors reported to promote parents' abilities or willingness to move towards an ASD identification for their child are summarized in Table 3. Thirteen facilitators were identified across the 18 studies, revealing four distinct themes: (1) knowledge, (2) proactive parent responses, (3) proactive provider responses, and (4) social and community supports/resources.

2.3.2 Comparisons to Daniels et al. (2014)

Barriers and facilitators that overlap with factors associated with age of identification found in Daniels et al. (2014) are indicated with asterisks (Tables 2 and 3). Barriers including "parent limited knowledge of ASD", "process involving many professionals”, “misidentification”, and “poverty” overlap with factors associated with later identification as reported by Daniels et al. Facilitators including “parent knowledge of child development”, “parent knowledge of/familiarity with navigating the identification process”, and “professionals who made referrals” overlap with factors associated with earlier identification as reported by Daniels et al.

2.3.3 Participant Characteristics

The barriers and facilitators above are derived from the experiences of a combined 1,002 caregivers of autistic children. Of the 971 participants for whom race/ethnicity were reported, 52.6% identified as White/Caucasian, 32.3% identified as Latino/Hispanic, 8.7% identified as Black/African American, 5.1% identified as Asian, 1.1% identified as Native American/American Indian, 0.7% identified as Multiracial, and 0.2% identified as Hawaiian/Pacific Islander. From studies in which age was reported, the majority of participants were in their 30s. From studies in which education level was reported (433 participants total), approximately 44.1% of participants held a high school degree or less while approximately 50.1% held a postsecondary degree. Studies 17 and 18 reported years of schooling, indicating that participants in these studies (384 participants total) had, on average, a high school degree or less. Due to variations in the reporting of income across studies (e.g., income brackets, text descriptions, averages, ranges), systematic aggregation of income could not be feasibly accomplished; however, participants represented a range of incomes from less than $10,000 to more than $100,000. Studies were most concentrated in the Midwestern region of the U.S. (S6-S8, S10, S12, S14, S16). Three studies collected data across multiple geographic regions (S11, S15, S17), and four studies explicitly sought participants from rural areas (S2, S4, S12, S15, S18). Participants were identified through a variety of means: ASD clinics, local ASD organizations, early childhood programs, school classrooms, research registries, parent support groups, and ethnic community informants and organizations using purposive and snowball sampling, emails, newsletters, flyers, phone calls, and social media (see Table 1).

2.3.4 Methodological Trends

The majority of the studies in this review were qualitative (S1-4, S6-10, S12-13, S15, S18), with two descriptive survey studies (S11, S17) and three mixed methods studies (S5, S14, S16). Data were collected through focus groups (S2, S4, S7, S15, S18), field observations (S6, S8), and quantitative measures or surveys (S5, S11, S14, S16-17) with interviews most widely used (S1, S3, S5-6, S8-10, S12-14, S18). All studies were retrospective. Studies 1, 15, 16, and 17 set restrictions on length of recall, requiring that children's ASD identifications occur within 3 to 6 months, 2 years, 6 months, and 5 years of data collection, respectively. Study 2 asked parents to only share identification experiences of their children who were 9 years or younger at the time of data collection.

Although "diagnosis", "assessment", "identification", "evaluation", and "screening" were included as search terms, 17 of the 18 included studies appeared to examine parent experiences obtaining a CD as opposed to an EE of ASD. Studies 13, 16, and 17 explicitly described clinical diagnostic criteria; however, all remaining studies either used the term "diagnosis" or suggested involvement of healthcare professionals in the identification process. Study 7 was the only study to specify that nine children had at least an EE of ASD with six also having a CD.

Six studies inquired about barriers to identification (e.g., "Tell me about the barriers to receiving an earlier diagnosis"; S4, S5, S11, S14, S17, S18), five studies inquired about both barriers and facilitators to identification (e.g., "What and who was helpful in finally getting a diagnosis? What got in the way of getting a diagnosis?"; S2-3, S12-13, S15), while seven studies neutrally inquired about parent experiences with the identification process (e.g., “Describe the process of how your child became diagnosed with an autism spectrum disorder”; S1, S6-10, S16).

Overall, this review revealed that the qualitative and descriptive literature on parent experiences in the ASD identification process is relatively recent, with publication years ranging from 2010 (S6) to 2021 (S1).

2.4 Discussion

This review examined parent-reported barriers and facilitators to ASD identification across qualitative and descriptive studies and how they compared with factors reported in Daniels et al. (2014). Participant characteristics and the methodological trends of this body of literature were also examined.

2.4.1 Barriers and Facilitators

This review identified a number of problem areas in the identification process. The most prominent theme was “dismissal of parent concerns” referring to dismissal from professionals, family and friends, and parents’ own denial of a problem. Of particular concern is the finding of dismissal of parent concerns from professionals, which is consistent with a recent study reporting that parent concerns may be dismissed for years (Constantino et al., 2020). Zuckerman et al. (2015) found that dismissive provider responses to parent concerns (i.e., saying nothing is wrong, it is too early to tell, or child might grow out of it) were associated with a 1-or-more year-increase in delay to diagnosis from when parents first raised concerns. The prominence of this theme may be related to the prominence of a second theme, “limited knowledge”, referring to limited knowledge and awareness of ASD amongst professionals, parents, and communities, as well as stigma associated with disabilities generally and ASD specifically.

In addition to barriers within these two themes, three notable stand-alone barriers include “parents not trusting professionals”, “professionals discrediting/devaluing parent insights”, and “lengthy process and wait times”. The first two barriers may be natural consequences of parents' concerns being dismissed by professionals. Of particular concern is "lengthy process and wait times". An already time-intensive process that requires sequential meetings with multiple professionals may be further exacerbated by a shortage of diagnostic services. Ning et al. (2019) found that diagnostic services were the least available type of ASD resource, representing just 9% of all the estimated ASD resources available in the U.S. Furthermore, the estimated average distance between an autistic individual and the nearest diagnostic service was approximately 22 miles, the furthest distance of all other ASD resources. In fact, of the 3,142 counties surveyed in the study, 84% did not have any diagnostic services available for children and families.

It is important to note that studies focused specifically on culturally and linguistically diverse (CLD) communities revealed legal and language barriers to identification that were not reported in other studies. Custodial arrangements of their child and fear related to immigration status were reported by parents in three studies (S3, S15, S17) to have hindered their ability to take steps towards an identification. Parents in 6 studies (S1, S2, S13, S15, S17, S18) reported that language prevented scheduling and attending appointments, limited their access to professionals and services, prevented their ability to advocate for their child and communicate concerns to professionals, and complicated their child's identification. Furthermore, interpretation services were poor or unavailable, and information provided in languages other than English were limited.

This review revealed much less about facilitators that can be bolstered to improve age of identification. The most prominent theme was "proactive professional responses", referring to professionals expressing concern for or encouraging evaluation, making referrals, and responding attentively to parent concerns. Lipkin et al. (2020) found that pediatricians' reported use of developmental screening tools have increased from 21% in 2002 to 63% in 2016. This finding is positive, given that Zuckerman et al.

(2015) found that proactive provider responses (i.e., suggesting parents discuss concerns with school, conducting developmental tests, and making referrals to specialists) were associated with at least a 1-year decrease in delay to diagnosis from when parents first raised concerns and that receiving multiple proactive provider responses was associated with even greater decreases in delay to diagnosis.

Other notable stand-alone facilitators include “parent persistence” and “supportive friends, family, and outside network”. The prominence of these latter facilitators are especially important given that studies suggest an ASD identification, in particular, is met with more challenges than other diagnoses. Autistic children tend to experience longer delays to identification and are less likely to encounter proactive provider responses compared to children with other intellectual and developmental disorders (Oswald et al., 2017; Zuckerman et al., 2015). Thus, parent persistence and social support may be particularly critical for moving towards an ASD identification.

In conclusion, twice as many parent-reported barriers as facilitators were identified. It is possible this finding is a true representation of parent experiences in the ASD identification process, which is that the process is laden with challenges. There are additional methodological considerations that may contribute to this finding. In the present review, barriers were explicitly examined in 11 studies while facilitators were explicitly examined in only five studies. Although seven studies neutrally asked parents about their experiences in the identification process, parents might have felt more inclined to share challenges if they perceived that the objective of the research was to address problems in the identification process. It is also possible that negative experiences are more memorable than positive experiences. Relatedly, recall bias is a limitation of this body of literature; only four of 15 studies set restrictions on length of recall. Whatever the explanation, it is clear that much less is known about facilitators to ASD identification. This information is a critical gap; whereas identifying barriers tells us what is not working in the identification process, identifying facilitators tells us what *is already* working. In efforts to improve the identification process and age of identification, bolstering facilitators may be more feasible than designing new solutions to address barriers.

2.4.2 Comparisons to Daniels et al. (2014)

A number of factors reported to impact identification were unique to each review. In contrast to Daniels et al. (2014), child variables such as cognitive ability, sex, and ASD severity were not reported by parents in this review to impede or expedite identification. It is possible that parents, on their own accord, do not perceive or share factors that potentially place blame on their child. Such variables may be better suited for detection through quantitative analysis. Parent education level was also not reported to impact identification in this review; however, other socioeconomic factors such as household income ("poverty") and related variables such as "work and time constraints", "costs of evaluation/limited insurance coverage", "lack of childcare" and "transportation challenges" were reported as barriers to identification. Additionally, this review identified a number of factors that were not addressed in Daniels et al. Overall, these appeared to represent constructs that may be difficult to operationalize, including barriers such as "community stigma", "parents perceiving racism/racial bias from professionals", and "cultural disconnect between professionals and parents" and facilitators such as "parent persistence" and "professionals who were attentive to parent concerns".

Despite these differences, several factors were identified in both reviews. As reported in the results, overlapping barriers included "parent limited knowledge of ASD", "process involving many professionals", "misidentification", and "poverty". Overlapping facilitators included "parent knowledge of child development", "parent knowledge of/familiarity with navigating the identification process", and "professionals who made referrals". The convergence of these factors underscore the importance of (a) ensuring parents have access to information on ASD and identification and (b) supporting professionals to be proactive partners in the identification process.

2.4.2.1 Ensuring Access to Information for Parents

Ensuring that all parents, especially parents from CLD communities, have access to information on ASD and identification remains a challenge to early ASD identification. Part of this challenge is due to a lack of comprehensive research in the area. Studies examining how parents seek ASD information have focused predominantly on Non-Latino White parents, indicating that parents commonly turn to books, the internet, other parents of autistic children, physicians, educators, and local and national ASD organizations (Gibson & Kaplan, 2015; Gibson et al., 2017; Grant et al., 2016; Mackintosh et al, 2005). Little is known about the information sources CLD communities turn to. One study found that Latino parents were significantly less likely than Non-Latino White parents to learn about ASD from the internet, books, magazines, healthcare professionals, friends, and other parents of autistic children (Magaña et al., 2013). This finding suggests that CLD families may not utilize or have access to the same information sources as Non-Latino White parents. To date, the most effective methods for presenting information to CLD communities remain unclear and require more research. Ensuring that all parents have access to information has the potential to overcome or remediate notable barriers such as “parent denial”, “parent limited knowledge of ASD”, and “community stigma”. It may also bolster facilitators such as “parent knowledge of child development”, “parent knowledge of the importance of identification”, and “parent knowledge of/familiarity with navigating the identification process”. This knowledge, in turn, may enable parents to be more “persistent”, another notable facilitator in the identification process.

2.4.2.2 Supporting Professionals as Proactive Partners

Although healthcare and educational professionals are both positioned to play early roles in the identification process, their abilities to do so are often compromised. The American Academy of Pediatrics (AAP) recommends that well-child visits with a pediatrician begin 3-5 days after birth and continue at intervals of a couple months until age three before continuing as yearly visits. Additionally, healthcare professionals are to screen for ASD at 18- and 24-month child-well visits (AAP, n.d.). Frequent check-ins beginning the first week of life and recommended ASD screenings mean that healthcare professionals are positioned to serve as parents' first access point to ASD identification well before children enter schools (Crais et al., 2014). Currently, however, healthcare professionals face numerous challenges in serving as early proactive partners for parents. The Modified Checklist for Autism in Toddlers with Follow-Up (M-CHAT/F)— the most widely used ASD screener— has lower specificity and positive predictive value in Black, Asian, and multiracial children and children with non-English exposure (Guthrie et al., 2019). Other barriers such as unfamiliarity with screening tools, inadequate reimbursement and time to screen for ASD during child-well visits, and lack of a systematic process for making and tracking referrals also hinder proactive actions (Zwaigenbaum et al., 2015). Furthermore, unlike other health conditions that can be diagnosed with definitive biological or genetic tests, an ASD identification relies in part on observation and professional judgment; this could mean that healthcare professionals hesitate to suggest ASD if they do not feel confident about their own knowledge of ASD, which may be further exacerbated when working with families whose culture they are unfamiliar with (La Roche et al., 2018). Indeed, fear of harming and upsetting parents in screening for or disclosing ASD concerns has been reported by healthcare professionals (Crais et al., 2014). Finally, doubts surrounding the benefit of early intervention in birth through age three also impact healthcare professionals' decisions to screen for ASD in an already tight appointment (Crais et al., 2014).

Educational professionals, likewise, face challenges to serving as proactive partners in the identification process. Although Part C provisions from IDEA require states to find children with and at-risk for disabilities and to provide them with early intervention services from birth, studies indicate that children with an EE of ASD are identified later than children with a CD of ASD (Esler et al., 2022; Pettygrove et al., 2013), suggesting that educators are second-in-line behind healthcare professionals in identifying ASD. It may be that families are not able to access early identification and intervention services until children begin school (i.e., state child find programs are not finding children with and at-risk for disabilities before they enter school). A lack of agreed upon diagnostic measures for assessing ASD in schools may also be a contributing factor. Klose et al. (2012) found that commonly-used tools for assessing ASD in schools (Autism Diagnostic Interview–Revised [ADI-R], Autism Diagnostic Observation Schedule [ADOS], Psychoeducational Profile–3rd Edition [PEP-3], Gilliam Autism Rating Scale–2nd Edition [GARS-2], and Childhood Autism Rating Scale–2nd Edition [CARS-2]) vary in their utility for identifying ASD based on IDEA and DSM criteria. The GARS-2 and CARS-2 showed the lowest utility but required the least training, took the least amount of time, and were also the most affordable to conduct.

Additionally, IDEA (2012) allows children from birth through age 9 to receive special education services under the nonspecific developmental delay (DD) eligibility, which may contribute to delays in identifying ASD in schools. DD is defined as significant developmental delays in one or more of the following areas: cognitive development, physical/motor development, communication, emotional development, or adaptive skills. Using data from the Autism and Developmental Disabilities Monitoring Network (ADDM), Rubenstein et al. (2018) found that the number of children with DD eligibility who met behavioral criteria for ASD had increased significantly from 2002 (5.2%) to 2010 (8.1%), suggesting that increasingly more autistic children are being served under a DD eligibility over time. It is possible that a subset of children who receive DD eligibility do not receive an EE of ASD because ASD was not accessed. Using 2018 ADDM data, Esler et al. (2022) found that when evaluations in educational settings resulted in DD eligibility, less ASD specific screening and diagnostic measures were used while the opposite was true when evaluations resulted in ASD eligibility. Furthermore, the study found that evaluations that resulted in a DD were less likely to document restricted repetitive behavior, specifically compulsions/rituals, fixated interests, and unusual sensory responses– a qualifying feature for ASD identification, in addition to social communication characteristics.

In sum, although healthcare and educational professionals are uniquely positioned to contribute significantly to ASD identification, it is clear a number of technical, personal, and system challenges prevent them from serving as proactive partners for parents in the identification process. Solutions beyond providing professionals with ASD training are needed. Research examining their experiences providing ASD screening and assessment may inform how healthcare and educational practices can be more conducive to the identification of ASD and other concerns. This may help to alleviate a number of parent-reported barriers such as “professionals’ dismissal/normalization of parent concerns”, “professionals discrediting/devaluing parent insights”, and “parents not trusting professionals”. It may also bolster facilitators such as “professionals who voiced concerns/encouraged evaluation”, “professionals who made referrals”, and “professionals who were attentive to parent concerns”.

2.4.3 Generalizability

Findings from this body of literature seem most generalizable to mothers of children with a CD of ASD in the U.S. With the exception of participant age and sex, which were predominantly 30s and female, a range of incomes, education levels, and geographic locations were represented. Approximately 50% of the aggregated participant pool also identified as representing a CLD community, although more research focusing specifically on Asian, Black, Hawaiian and Pacific Islander, and Native American communities are needed. The collective range of recruitment methods used (from clinic- to community-based sampling) reduce the influence of sample bias on the findings of this literature (Conrad, 1990).

There are limitations to generalization, however. As this literature seems to have predominantly captured parents' experiences obtaining a CD of ASD, parents' experiences obtaining an EE remain unclear. There is reason to believe that these experiences would differ. First, obtaining a CD may require more parent initiation and proactivity than an EE. Federal identification and evaluation standards set forth in IDEA (2012) require schools to play an active role in the identification of children with disabilities including ASD. Because a CD is not mandated by federal law, parents may have to take active measures to obtain a CD. Thus, parents may perceive less barriers and more facilitators when seeking an EE of ASD and may perceive the opposite effect when seeking a CD. A second limitation to generalization is that the experiences captured in this literature represent the experiences of parents whose children ultimately received an ASD identification. The presence and/or absence of barriers and facilitators encountered by parents whose children never received an identification are unclear and require more research.

2.4.4 Limitations

It is possible the selection of barriers and facilitators and the categorization of them in this review are biased by my personal experiences. This review included multiple independent coders to protect against this bias. I also made transparent my positions and experiences related to this topic, practiced researcher reflexivity at each coding meeting, and conducted peer reviews with research members who did not participate in coding. It is also possible my interpretation of findings from primary studies are in line with my own understanding of the identification process and differ from that of the original authors. As a protective measure, I substantiated the barriers and facilitators in Tables 2 and 3 with direct excerpts from respective primary studies. A third shortcoming of this review is related to the nature of qualitative and descriptive inquiry. I identified a list of barriers and facilitators by examining parent reports of their experiences in the identification process. Whether these factors truly impact age of identification is out of the scope of qualitative and descriptive studies. This limitation serves as another push for the use of multiple methods of inquiry in understanding a phenomenon.

2.4.5 Conclusion

Through a critical analysis of parent-reported barriers and facilitators to ASD identification, participant characteristics, and methodological trends, this review reveals the importance of (a) ensuring that parents, including CLD parents, have adequate access to information on ASD and identification and (b) supporting healthcare and educational professionals to be proactive partners in the identification process. Convergence with quantitative findings from Daniels et al. (2104) further strengthens these recommendations. This review also demonstrates that quantitative and qualitative/descriptive findings reveal unique barriers and facilitators to identification, demonstrating that both forms of inquiry are necessary for understanding the breadth of barriers and facilitators that parents encounter.

Chapter 3: Hmong Parents' Beliefs About Autism and Their Experiences in the Identification Process

3.1 Introduction

For autistic individuals and their families, an identification of autism spectrum disorder (ASD) can validate long-held observations and concerns, provide answers to long-awaited questions, alleviate guilt and self-blame, open connections to the autistic community, and perhaps also provide a new social identity (Anderson-Chavarria, 2021; Cooper et al., 2017; Watson et al., 2008). Additionally, the earlier ASD is identified, the earlier individuals and their families can start receiving the supports and services they need. Individuals can be identified for ASD through an educational eligibility or a clinical/medical diagnosis. An educational eligibility provides Part C early intervention services for children birth through age 3 and Part B special education services for children age 3 through 21 through the Individuals with Disabilities Education Act (IDEA, 2012). In contrast, a clinical diagnosis provides access to services outside of school such as Early Intensive Developmental and Behavioral Intervention (EIDBI) and other waiver-based services and supports. A clinical diagnosis also guarantees some extent of insurance coverage for ASD services in all 50 states and Washington D.C., thereby enabling families to utilize services that they otherwise may not be able to afford (National Conference of State Legislatures, 2021). (In this paper, the term "identification" is used to refer to both an educational eligibility and clinical diagnosis of ASD.) Receiving services early is crucial as decades of research have demonstrated that intensive intervention during the first several years of life when brain development is most amenable to intervention (Knickmeyer et al., 2008; Markant & Thomas, 2013) can improve long-term outcomes for autistic individuals (e.g., Wetherby & Woods, 2006; Dawson et al., 2010; Dawson et al., 2012; Estes et. al., 2015; Landa, 2018; Reichow, 2012; Wetherby et al., 2018; Zwaigenbaum et al., 2015). Access to early intervention services, in addition to the social-emotional supports mentioned previously, makes the early identification of ASD especially important.

Parents are particularly apt to support early identification. They are often the first to notice and raise concerns about their child's development and often do so prior to age 2 (Chawarska et al., 2007; Sansosti et al., 2012; Wong et al., 2017). Moreover, parents' concerns are generally indicative of a diagnosis, regardless of parent education level, socioeconomic status, and child-rearing experiences (Glascoe, 1999; Glascoe & Marks, 2011). Parents are also often the ones to navigate their child's identification processes and play key roles. Tasks such as learning about ASD, retrieving accurate information, finding providers, scheduling and attending appointments, contributing information to assist with evaluations, completing paperwork, and securing child care generally fall on parents. Thus, enabling parents to take steps towards identification at the onset of their concerns can significantly support the early identification of ASD. Examining parents' experiences in the identification process may inform ways parents can be supported to do so. In this study, the identification process is defined as starting when concerns about a child's development are first recognized, including screening, referrals, and evaluations, and ending with the receipt of an educational eligibility or clinical diagnosis of ASD.

Although a number of studies have examined parents' experiences in the identification process (see Study 1 for a review of parent-reported barriers and facilitators from qualitative and descriptive studies), less is known of the experiences of parents from underserved, culturally and linguistically diverse (CLD) and recent immigrant/refugee communities (Bogenschutz, 2014; Welterlin & LaRue, 2007). The term CLD in this paper follows the definition provided by Sullivan (2011), referring to racial/ethnic minority groups and groups with native languages other than English in the U.S. This research is warranted as the current identification process likely better supports White, middle-class, English-speaking families: healthcare providers are disproportionately White (LeLacheur et al., 2015); pediatric providers are less comfortable and less likely to screen for ASD with non-English-speaking families (Zuckerman et al., 2013); the Modified Checklist for ASD in Toddlers with Follow-Up (M-CHAT/F) has lower specificity and positive predictive value in Black, Asian, and multiracial children and children with non-English exposure (Guthrie et al., 2019); commonly-disseminated early signs of ASD (e.g., lack of eye contact, lack of pointing, and language delays) emphasize Western cultural ideas of typical development (Ennis-Cole et al., 2013) and may not be recognized by other cultural groups as indicative of a disability, let alone ASD (Donohue et al., 2019); and information on ASD in languages other than English is limited (Sakai et al., 2019; Stahmer et al., 2019). Altogether, these conditions likely make it more difficult for CLD parents to take steps towards an ASD identification.

Not surprisingly, a number of studies show that CLD parents experience inequities throughout the identification process. Constantino et al. (2020) found that Black parents' concerns about their child's development were dismissed by providers for several years. Christensen et al. (2018) and Valicenti-McDermott et al. (2012) found that children of color and children of foreign-born mothers receive fewer and later ASD evaluations. Similarly, Zeleke et al. (2019) found that significantly less CLD parents reported receiving ASD screenings and evaluations than Non-Latino White parents. Pertaining to age of an ASD identification, Magaña et al. (2013) and Mandell et al. (2002) found that CLD children were identified one to two years later than Non-Latino White children. There may also be inequities in the type of ASD identification CLD children receive. Esler et al. (2022) found that Black, Asian, and Hispanic children were more likely than Non-Latino White children to have educational records of ASD alone as opposed to health records of ASD or both; interestingly, children who only have educational records of ASD were identified on average approximately two years later than children with health records of ASD and children with both. Overall, Zeleke et al. (2019) found that CLD parents were less satisfied than Non-Latino White parents with the diagnostic services they received from both healthcare and educational systems. Altogether, these findings call for more research intentionally focused on understanding and improving CLD parents' experiences in the identification process.

One CLD community that has received very little attention in ASD research is the Hmong community— a Southeast Asian refugee group with a U.S. population of approximately 310,000 and one of the fastest-growing ethnic groups in the U.S (Asian American Center for Advancing Justice, 2015). The first Hmong families arrived in the U.S. in 1975 as refugees after Laos fell to communist forces during the Vietnam War. A second wave of approximately 15,000 Hmong refugees arrived in the U.S. in 2004 after the closing of Wat Thamkrabok, a Buddhist temple compound that housed Hmong refugees who did not want to relocate to another country post-war (Minnesota Historical Society, n.d.; Public Broadcast Station, n.d.). In comparison to the general U.S. population, the Hmong community is more likely to be English language learners, to live in poverty, to rely on public assistance programs, to have lower educational attainment, and to have public versus private health insurance (American Community Survey, 2017). Such factors may mean that Hmong children are particularly vulnerable to inequities in identification, making it especially necessary that we understand how to support Hmong parents to take steps towards an ASD identification. Looking at parents' experiences in the identification process may inform ways to do so.

3.1.1 Parents' Experiences in the Identification Process

Studies looking at parents' experiences in the ASD identification process reveal that parents encounter a number of barriers and facilitators that affect their ability to get a timely identification for their child (Daniels & Mandell., 2014; Martinez et al., 2018;

Study 1). Studies focused on U.S. parents reveal barriers pertaining to (a) healthcare professionals (e.g., dismissal of parent concerns, misidentification, lack of trust); (b) parents (e.g., limited ASD knowledge, denial, work schedules); (c) identification services (e.g., service shortages, long waitlists); and (d) community (e.g., stigma, low ASD awareness; Elder et al., 2016; Hidalgo et al., 2015; Kalash et al., 2012; Lappé et al., 2018; Moodie-Dyer et al., 2014; Narcissa et al., 2012; Sansosti et al., 2012; Wong et al., 2017). Studies focused on parents from CLD communities reveal additional barriers including differential treatment, cultural disconnect with professionals, lack of child care, transportation challenges, poverty, immigration status, and language barriers (Dabanah et al., 2018; Jegatheesan et al., 2010; Pearson & Meadan, 2018; Sakai et al., 2019; Stahmer et al., 2019; Zuckerman et al., 2017; Zuckerman, Sinche, Mejia, et al., 2014).

Pertaining to facilitators to identification, studies focused on U.S. parents report media exposure, knowledgeable professionals, parent persistence, social support, and parent knowledge of ASD, child development, and the importance of identification (Hidalgo et al., 2015; Kalash et al., 2012; Lappé et al., 2018; Moodie-Dyer et al., 2014; Sansosti et al., 2012; Wong et al., 2017). Studies focused on facilitators reported by CLD parents emphasize the importance of professionals who take time to listen and understand parent concerns (Dababnah et al., 2018; Jegatheesan et al., 2010; Pearson et al., 2018; Sakai et al., 2019; Stahmer et al., 2019).

Very few studies have examined Hmong parents' experiences in the identification process. Hmong parents in a qualitative study conducted by the Minnesota Department of Health (MDH; 2014) reported barriers including a lack of knowledge about ASD and resources, competing demands, denial, stigma, dismissal of concerns from providers, long wait lists for services, a complex identification process, and the lack of insurance coverage for evaluations. Additionally, Bogenschutz (2014) interviewed three Hmong parents of children with intellectual and developmental disabilities and found that finding accurate information about specific disabilities, healthcare providers, and insurance were particularly difficult. Much less is known of facilitators Hmong parents encounter in the identification process. One Hmong mother in Bogenschutz (2014) reported that it was helpful when doctors allowed interpreters enough time to interpret as medical ideas related to disability are often difficult to understand in Hmong. Currently, it is unclear what barriers and facilitators Hmong parents encounter and how the combination of these barriers and facilitators affect Hmong parents' ability to move towards ASD identification.

3.1.2 Parents' Beliefs Related to ASD

In addition to barriers and facilitators, the knowledge and beliefs parents bring into the identification process can also influence a timely ASD identification. Parents' awareness of ASD and their views on early identification and intervention can have a passive, proactive, or even debilitating effect on their steps towards an identification. Parents with limited knowledge of ASD and other disabilities may not see reasons to start the identification process for a disability. Similarly, parents who do not know that identification of a disability can provide access to intervention and those who do not believe that intervention can improve outcomes may not think it is necessary to seek an identification. Alternatively, parents who are aware of ASD and who hold positive views of identification and intervention may be more motivated (Lappé et al., 2018; Wong et al., 2017). One Hmong mother from Moua (2014) expressed motivation to find as many supports as possible for her child because of the belief that intervention can help autistic children be more successful. Finally, parents who perceive harm from an ASD identification or intervention may be more hesitant to seek an identification. Hmong parents in MDH (2014) shared the perception that parents of autistic children could be blamed for their child's ASD. Such negative perceptions of ASD may deter Hmong parents from seeking an ASD identification. Indeed, stigma, shame, and fear are not unique to Hmong parents and are also reported by parents across racial/ethnic groups as deterrents to identification (Dababnah et al., 2018; Elder et al., 2016; Hidalgo et al., 2015; Sakai et al., 2019; Stahmer et al., 2019; Zuckerman, Sinche, Mejia et al., 2014).

Several studies also suggest that what parents believe causes their child's ASD can influence their identification decisions. For example, parents who do not see their child's condition as having a medical cause may be less likely to bring concerns to healthcare professionals (Mandell & Novak, 2005; Zuckerman, Sinche, Cobian et al., 2014). Few studies have looked at Hmong parents' perceptions of the causes of ASD and other disabilities. These studies reveal that genetics is a prominently-perceived cause of ASD, although drugs, medications, diet, alcohol, and spiritual causes such as karma, reincarnation, a child's name, and a child's lost or wandering soul are also perceived causes of ASD (Fujii & Vang 2011; MDH, 2014; Thao, 2010). A better understanding of Hmong parents' knowledge and beliefs about early identification, intervention, and the causes of ASD may provide important insight as to why Hmong parents do or do not seek an ASD identification.

3.1.3 Purpose

In summary, the literature suggests that the course of action parents take— or are able to take— towards an identification may in part be influenced by their identification experiences and their beliefs/knowledge related to ASD going into the identification process. To date, our understanding of the identification experiences and ASD beliefs of Hmong parents are limited, as only a handful of published studies have examined ASD in the Hmong community (e.g., Bogenschutz, 2014; Estrem & Zhang, 2010, MDH, 2014). As Hmong children are particularly vulnerable to identification inequities, more research in this area may inform ways to better support Hmong parents to take steps towards an ASD identification. Thus, this study addresses three research questions:

1. What are Hmong parents' beliefs about early identification, intervention, and the causes of ASD?;
2. What barriers and facilitators do Hmong parents encounter during the identification process?; and
3. What are potential predictors of age of identification for Hmong children that may be worthy of investigation in future studies?

3.2 Methods

3.2.1 Participants

Participants were Hmong caregivers who were at least 18 years of age, residing in the U.S., and who had a child with an educational eligibility and/or clinical diagnosis of ASD at the time of the study. A description of the study and Hmong and English fliers were shared with Hmong education and disability-related Facebook groups and pages (Supporting all Abilities, Welcoming all Voices, Ua Tau, Hmong Health Care Professionals Coalition, Hmong Youth Parents United, Hmong Early Childhood Coalition, and Hmong American Experience), Hmong charter schools in the Minneapolis and St. Paul areas, St. Paul Public schools, an ASD mental health service center in Minneapolis, a university research registry, a Hmong dual language school in Wisconsin, and Hmong disability service providers and educators in Wisconsin, Minnesota, and California. Because data collection took place during the COVID-19 pandemic (mid October 2021 to February 2022), recruitment efforts were largely limited to online dissemination of the survey (e.g., social media postings, emails).

Given that data collection was anticipated to occur predominantly online, an elaborate participation process was put in place to protect the integrity of the survey responses. Interested participants could either scan the QR code or visit the browser link shared on the flier which directed them to an intake survey. After reviewing a detailed overview of the study, participants were asked to indicate if they would like to participate.

Those who indicated “yes” were directed to a series of screening questions for eligibility. The intake survey automatically ended for participants who failed the screening questions. Multiple submissions from the same device were disabled. Those who passed screening questions were directed to an electronic consent form. Participants who completed the consent form indicated how they would like to take the survey: (a) online via Qualtrics ®, (b) by paper, or (c) through a one-on-one virtual interview (this option was provided for participants who required Hmong language or other support to complete the survey). Those who selected to take the survey online were provided a Qualtrics ® link. Those who selected to take the survey via paper or one-on-one interview were asked to provide contact information. One participant with limited English proficiency selected to take the survey via a Zoom interview; all other participants completed the survey online. A $10 cash or Amazon gift card was provided as incentive to those who completed the survey. Written informed consent was obtained for all participants. For the participant who completed the survey via Zoom, a copy of the consent form was emailed prior to the meeting and was reviewed and completed at the beginning of the meeting before starting the survey. Study procedures were approved by the Institutional Review Board at the University of Minnesota.

A total of 35 caregivers participated in the study, a majority of which were recruited via Facebook postings (*n* = 30, 85.7%). On average, participants were 36.77 years old (*SD* = 5.54, Range = 27 - 47), most had at a postsecondary degree (*n* = 27, 77.1%), and a little more than half (*n* = 20, 57.1%) had a household income greater than $80,000. Most participants were from Minnesota (*n* = 16) and Wisconsin (*n* = 10), and most reported living in suburban and urban areas (*n* = 30). The average age at which participants first had concerns about their child’s development and first shared these concerns with a healthcare provider or educator were 1.87 years (*SD* = 1.36, Range = 0 - 6) and 2.09 years (*SD* = 1.27, Range = 0 - 6), respectively. The average age at which their child was first identified with ASD was 4.13 years (*SD* = 2.29, Range = 1.33 - 13). The first form of ASD identification was a clinical diagnosis for 20 children (57.1%) and an educational eligibility of ASD for 15 children (42.9%). Children who first received a clinical diagnosis were identified on average at 3.72 years of age (*SD* = 2.68, Range = 1.33 - 13.00), whereas children who first received an educational eligibility of ASD were identified on average at 4.67 years of age (*SD* = 1.57, Range = 2.5 - 7.5). This difference in age of identification was not significant, (1, *N* = 35) = 13.90, *p* = .606. Twenty-nine (82.9%) children went on to receive both forms of identification. Fifteen children (42.9%) were previously identified with a developmental delay, and eight (22.9%) also had an intellectual disability. The children represented in this study were predominantly male (*n* = 30, 85.7%) and were on average 9.37 years of age at the time of the study (*SD* = 4.77, Range = 2 - 22). Considering the children's current ages and the ages at which they were first identified, participants were recalling information about the identification process from 5.25 years on average (*SD* = 4.68, Range = 0 - 18). Participant characteristics are presented in Table 4.

3.2.2 Measure

I developed the Parent Perceptions of Autism Spectrum Disorder (PP-ASD) survey to gather parents' knowledge and beliefs related to ASD (i.e., their beliefs about early identification, intervention, and the causes of ASD), the barriers and facilitators they encountered to getting their child identified, and the sources parents use to access information on ASD. The PP-ASD was informed by the available ASD literature as well as findings from a systematic review of parent-reported barriers and facilitators to ASD identification (Study 1) and was created on Qualtrics ® using survey guidelines from Halaydna and Rodriguez (2013) and Dillman et al. (2014). The PP-ASD was piloted with a convenience sample of parents of autistic children from a university research registry (*N* = 114) and was recently used with a community sample in Chaxiong (2020; *N* = 205).

To ensure that the PP-ASD was appropriate for use with Hmong parents, I conducted three one-on-one virtual think-alouds with two Hmong mothers and one Hmong father of autistic children ages 3 through 24. The father and one mother spoke English while the second mother required the think-aloud to be conducted in Hmong. During the think-alouds, parents were asked to “process” the survey aloud, beginning by reading each question, sharing reactions, and then responding to the question. These think-alouds led to a number of minor changes to the PP-ASD (e.g., questions were reworded and reordered, new response items were added) and two notable decisions: (1) the term “test” (e.g., “which of the following made it hard to get your child tested for autism?”) replaced “evaluate”, “diagnose", and “identify” based on parent feedback that the varying terms posed confusion given that the perceived meaning of all three were similar and “test” was easiest to understand; and (2) despite the initial goal to offer a translated Hmong version of the PP-ASD, parent feedback led to the decision to offer one-on-one virtual interviews in Hmong instead. Parents shared that because many English disability and education terms do not have direct Hmong equivalents (e.g., “genes”, “toxins”, “identification”, “developmental delay”, “intellectual disability”), accurately translating certain terms would require lengthy descriptions, making a Hmong-translated version effortful to read and comprehend. It was determined that one-on-one conversation may be more conducive to lengthy descriptions and would also allow participants to ask clarification questions to ensure ideas were communicated accurately. Think-alouds were screen-recorded and deleted once feedback was incorporated into the PP-ASD. The revised PP-ASD took approximately 30 minutes to complete. (The PP-ASD can be viewed at https://z.umn.edu/Chaxiong_PP-ASD.)

3.2.3 Statistical Analyses

Descriptive statistics (i.e., means, percentages) were used to answer Aims 1 and 2. Prominently-reported barriers and facilitators were highlighted, defined as those reported by >50% of Hmong parents.

To address Aim 3, two stepwise linear regressions were conducted. A backward stepwise linear regression was first used to identify potential predictors of age of identification from six candidate variables based on the literature: sex (female or male), type of first ASD identification (educational eligibility or clinical diagnosis), intellectual disability diagnosis (yes or no), who pushed the most for an ASD identification (parent or other), number of barriers reported, and number of facilitators reported. Sex was included because studies have shown that ASD is four times more prevalent among male children than female children (Maenner et al., 2021) and may be harder to detect in female children (Dworzynski et al., 2012; Kirkovski et al., 2013). Type of first ASD identification was included because studies have found that children identified in schools have later ages of identification than children identified in healthcare settings (Esler et al., 2022; Wiggins et al., 2006). Receipt of an intellectual disability diagnosis was included as studies have also shown that autistic children with lower intelligence quotients are identified earlier than children with higher intelligence quotients (Maenner et al., 2021). As parents are often the first to notice concerns about their child's development (Sansosti et al., 2012; Wong et al., 2017), whether parents or someone else (e.g., doctor, teacher, other service provider, family/friend) pushed the most for an ASD identification could have an effect on age of identification and thus was included as a possible predictor. Finally, number of barriers and facilitators reported by parents were included as it would seem likely that encountering fewer barriers and more facilitators would be associated with earlier ASD identification. A backward stepwise regression begins by including all six candidate variables in a full model, and the variable that contributes the least is selected for elimination by computer algorithm based on AIC (i.e., variables that increase the AIC of the full model); this process is repeated with the remaining variables until only contributing variables remain in the final model.

Next, a forward stepwise linear regression was conducted to identify barriers and facilitators that are potential predictors of age of identification. Candidate variables were prominent barriers and facilitators (i.e., those reported by >50% of Hmong parents). In contrast to a backward stepwise linear regression, a forward stepwise regression begins with a model that contains no variables; the most significant variables are selected for entry one at a time by computer algorithm based on AIC. For this reason, a forward stepwise linear regression is especially suited for exploratory analysis when there is a high number of candidate variables (Choueiry, n.d.).

Stepwise regressions were conducted in lieu of hierarchical linear regressions, arguably a more sound alternative for the sequential analysis of variables (Lewis, 2007). This decision was made because of a lack of theory for which to inform the order variables should be entered, which is important for hierarchical linear regressions. Stepwise regressions rely on computer software algorithms to select variable order and were chosen for this reason. Although stepwise regressions have important limitations to consider (e.g., they do not consider all possible combinations of candidate variables; they do not necessarily select the best predictors; they report potentially biased effect sizes and p-values), they are a useful statistical tool for exploratory analyses of topics with limited research (Choueiry, n.d.; Lewis, 2007). All analyses were conducted in R (R Core Team, 2019). The olsrrr R package was used to conduct the backward and forward stepwise regressions.

3.3 Results

3.3.1 Beliefs Related to ASD

Overall, the participants in this study reported awareness of ASD and believed early identification and intervention were important. Thirty participants (85.7%) reported that their child's ASD identification is most credited to the actions of them or their spouse. This role was reported by two participants to have been filled by a family member or friend, by one participant to have been filled by a teacher, and by one participant to have been filled by a service provider. Prior to their child's ASD identifications, 26 participants (74.3%) reported knowing what ASD was; of this subset, 20 participants (76.9%) reported suspecting that their child had ASD. Participants who did not know about ASD and those who knew but did not suspect it commonly reported thinking instead that their child had a developmental delay or speech and communication challenges. The majority of participants (97.1% - 100%) agreed or strongly agreed that (1) their child's identification of ASD is accurate; (2) it is important to know as early as possible if their child has ASD; (3) knowing that their child is on the spectrum allows them to obtain services; (4) receiving services early is important; and (5) receiving services can help their child in the future. Seven participants (20.0%) agreed or strongly agreed that an ASD identification could harm their child. Pertaining to perceived causes of ASD, atypical brain development (62.9%) and genetics (60.0%) were prominently-reported as currently-held perceived causes. Spiritual causes (i.e., child's name, lost or stolen soul [of child], karma or punishment, God's will, and tragedy from past life) in addition to allergies (of child) and bad parenting were among some of the least endorsed causes of ASD. Endorsement of each perceived cause is presented in Table 5.

3.3.2 Parent-Reported Barriers and Facilitators to Identification

On average, the identification process (e.g., from first concerns to receipt of an educational eligibility or clinical diagnosis of ASD) took a duration of 2.13 years (*SD* = 2.25, Range = 0 - 11). More specifically, the average wait time from when participants first had concerns to when they first shared these concerns was .18 years or two months

(*SD* = 1.19, Range = 0 - 2.25); from this point to receipt of an identification was an additional 2.04 years (*SD* = 2.27, Range = 0 - 9.5).

Throughout this process, participants reported on average 9.37 barriers to identification (*SD* = 5.84, Range = 0 - 20). There were five prominently-reported barriers: “Autism is not talked about in the Hmong community” (65.7%); “the process to get my child tested for autism was long” (65.7%); “I had to wait a long time before my child could get an appointment to be tested for autism” (54.3%); “autism is seen as a bad thing in the Hmong community” (57.1%); and “I did not want to believe that my child has a disability” (51.4%). Parent-reported barriers are presented in Table 6.

Conversely, participants reported on average 12.71 facilitators to identification (*SD* = 3.40, Range = 7 - 20). There were 14 prominently-reported facilitators: “I kept pushing and trying” (97.1%); “I could speak and understand English” (94.3%); “I tried to find my own information” (82.9%); “I knew about child development” (80.0%); “I knew about autism” (77.1%); “my child showed many signs of autism” (74.3%); “teachers listened to my concerns” (74.3%); “teachers were knowledgeable about autism” (74.3%), “doctors listened to my concerns” (71.4%); “doctors were knowledgeable about autism” (65.7%); “teachers encouraged me to get my child tested for autism” (57.1%); “doctors referred me to someone who could test my child for autism” (57.1%); “family/friends were supportive” (51.4%); and “I knew someone with autism” (51.4%). Parent-reported facilitators are presented in Table 7.

3.3.3 Potential Predictors of Age of Identification

To identify possible predictors of age of identification for investigation in future studies, two stepwise linear regressions were conducted. A backward stepwise linear regression was first conducted with six candidate variables selected based on previous literature: sex, type of first ASD identification, intellectual disability diagnosis, who pushed the most for an ASD identification, number of barriers reported, and number of facilitators reported. None of these variables were selected as predictors of age of identification based on AIC.

Next, a forward stepwise linear regression was conducted with the five prominently-reported barriers and the 14 prominently-reported facilitators (a total of 19 candidate variables). Candidate variables to explore in future studies were reduced to three variables: “Autism is not talked about in the Hmong community” and “teachers encouraged me to get my child tested for autism” as factors expediting age of identification and “teachers listened to my concerns” as a factor impeding age of identification.

3.4 Discussion

This study examined (1) Hmong parents’ beliefs related to ASD, (2) parent-reported barriers and facilitators to ASD identification, and (3) potential predictors of age of identification for Hmong children. The results suggest that the majority of Hmong parents in this study played active roles in their child’s ASD identifications, were aware of ASD, and believed that early identification and intervention are important. Despite generally positive perceptions, it should be noted that seven participants (20.0%) believed an ASD identification could harm their child. Due to the use of survey methodology, it is unclear whether parents interpreted harm here as pertaining to the ASD “label” or to the identification “process”. Parents have reported that screening and evaluations can be uncomfortable for their child and can cause harm including psychological distress and parent-child relational strains (Petruccilli et al., 2021; Zuckerman et al., 2017; Zuckerman et al., 2014). Pertaining to perceived causes of ASD, genetics— the causal factor with the most research support— was one of two prominently-reported perceived causes (de la Torre-Ubieta et al., 2016), aligning with findings from previous studies with Hmong parents (MDH, 2014; Thao, 2010). Altogether, these results suggest that the Hmong parents in this study held perceptions of ASD, identification, and intervention that align with conclusions of conventional research in these areas.

Pertaining to barriers and facilitators, Hmong parents in this study reported encountering a higher number of facilitators than barriers, despite the identification process taking on average two years. Additionally, there were nearly three times more prominently-reported facilitators than barriers. The five prominently-reported barriers underscore the need to address stigma surrounding ASD and other disabilities as well as the lengthy identification process– issues not unique to the Hmong community (Study 1). The 14 prominently-reported facilitators underscore the importance of enabling parents to take action towards an identification, as the top-reported facilitators were all parent-related (e.g., “I kept pushing and trying”, “I tried to find my own information”, “I knew about child development/autism”). Ensuring that information about autism and identification are available in the places that Hmong parents access may be one way to enable parents to do so. Prominently-reported facilitators also highlight that healthcare providers and educators can be key partners in helping parents move towards an identification. The Hmong parents in this study reported more barriers pertaining to doctors and more facilitators pertaining to teachers, suggesting that educators were perceived as more supportive partners than healthcare providers in the identification process.

The reporting of more facilitators in this study is somewhat conflicting as previous studies examining barriers and facilitators reported by CLD parents indicate a much greater number of barriers than facilitators (e.g., Dabanah et al., 2018; Jegatheesan et al., 2010; MDH, 2014; Pearson & Meadan, 2018; Sakai et al., 2019; Stahmer et al., 2019; Zuckerman et al., 2017; Zuckerman, Sinche, Mejia, et al., 2014). It is possible that although a larger inventory of barriers are reported among parents, only a handful are frequently encountered. In contrast, a smaller inventory of facilitators are reported among parents, but many are frequently encountered. The reporting of more facilitators in this study may also be due to the fact that eight of the 20 facilitators were parent actions (e.g., “I knew about autism”, “I tried to find my own information”, “I kept pushing and trying”)-- actions that would likely be endorsed by parents who played active roles in their child’s identification process, were aware of autism and who believe early identification and intervention are important.

Given these findings, it is not surprising that the average age of identification for the children in this study (4.13 years) matches that of the national average (4.17 years; Maenner et al., 2021). Although the literature suggests that age of identification may be particularly late for CLD children, this was not the case with the Hmong children in this study. These findings should be considered in light of the fact that the Hmong parents in this study were fairly well educated with middle to high family incomes and only one participant indicated having limited English.

In the first exploratory analysis of potential predictors of age of identification, the backward stepwise linear regression selected none of the six candidate variables suspected to predict age of identification. Sex (female and male) and who pushed the most for an ASD identification (parent and other) may not have had enough participants in each level to show effects (i.e., only five children were female and only five parents reported that someone other than themselves were the ones who pushed for their child’s ASD identification). Regression slope coefficients were not reported nor interpreted as stepwise regressions produce biased effect sizes. It is also possible that the sample size in this study was too small to detect effects. Power analysis (f^2 = .544, alpha = .05, and power = .95) based on pilot data of the PP-ASD (Chaxiong, 2020) indicated that a sample size of N = 48 was needed. This study included a sample size of N = 35, limited by recruitment capabilities during the COVID-19 pandemic.

In the second exploratory analysis, the forward stepwise linear regression selected two facilitators and one barrier as potential predictors of age of identification out of 19 prominently-reported barriers and facilitators. As expected, “teachers encouraged me to get my child tested for autism” (a facilitator) was associated with earlier age of identification. The relations of the two remaining variables to age of identification were unexpected. “Autism is not talked about in the Hmong community” was associated with earlier age of identification (despite being a barrier). It is possible that parents who reported this barrier had high awareness of ASD or had been able to engage in conversations about ASD outside of the Hmong community (contributing to early age of identification) and, from these vantage points, perceived little conversation about ASD occurring in the Hmong community. Secondly, “teachers listened to my concerns” was associated with later age of identification (despite being a facilitator). For these parents, it is possible that teachers were the first to listen to their concerns when previous providers had not (contributing to later age of identification). It is also possible that their children had later emerging ASD that did not become evident until school age. To summarize, although parents report certain things as being helpful or impeding in the identification process, these things may not necessarily influence age of identification in those ways. Survey methodology limits the ability to gather further insight on this phenomenon. More research, perhaps one-on-one interviews or focus groups, is needed.

3.4.1 Limitations

This study has several important limitations to consider. The PP-ASD is a retrospective survey and relies on parent recall which is susceptible to errors such as reduced accuracy and change in thinking (Ozonoff et al., 2018). Children’s ASD identifications were also based on parent report and were not independently verified. ASD severity or degree of impairment was not accounted for, which may moderate age of identification (e.g., those not identified until school age may have fewer symptoms; those with profound ASD may be identified earlier). Results from exploratory analyses to identify potential predictors of age of identification for investigation in future studies should be considered in light of the limitations of stepwise regressions noted previously in the methods section. Finally, this is not a representative sample of Hmong parents. COVID-19 largely limited the recruitment of participants to online postings, and as a result, the majority of participants came from postings in disability, education, and ASD Facebook groups and pages. Parents who are a part of these groups may qualitatively differ from parents who are not. As previously described, the parents in this study were also fairly well educated, had middle to high family incomes, and only one parent required Hmong language support to complete the survey. Future studies with a more representative sample of Hmong parents are needed.

3.4.2 Conclusion

Overall, the Hmong parents in this study reported being aware of ASD and holding positive perceptions of identification and intervention, which the literature suggests may facilitate steps towards an earlier identification. The parents in this study also reported encountering more facilitators than barriers, and these underscore the need to address stigma surrounding ASD and the lengthy identification process and enabling parents to be proactive in the identification process. Research with a larger and a more representative sample of Hmong parents is needed to better understand Hmong parents' beliefs about ASD and their experiences in the identification process.

Chapter 4: A Preliminary Examination of the Information Sources Hmong Parents Use to Learn About Autism

4.1 Introduction

Ensuring that parents, especially parents from culturally and linguistically diverse (CLD) communities, have adequate access to information on autism spectrum disorder (ASD) remains a challenge (Crais et al., 2020; Sakai et al., 2019; Stahmer et al., 2019). Studies that have examined the sources parents turn to for ASD information indicate that books, the internet, other parents of autistic children, doctors, educators, local and national ASD organizations, and service providers are common sources (Gibson & Kaplan, 2015; Gibson et al., 2017; Grant et al., 2016; Hrdlicka et al., 2016; Mackintosh et al, 2005; Mansell & Morris, 2004). These studies, however, have predominantly focused on White, middle class, English-speaking participants or have not provided information on cultural and linguistic diversity. Lack of knowledge surrounding the information-seeking behaviors of CLD parents is problematic as decisions to seek ASD identification (i.e., a clinical diagnosis or eligibility for special education services under ASD) and intervention services are heavily influenced by what parents know and the information sources they use (Frame & Casey 2019; Minnesota Department of Health [MDH], 2014; Pearson et al., 2018; Wong et al., 2017). Indeed, a number of studies show that children from CLD communities are less likely to receive ASD identifications (Maenner et al., 2020; Travers & Krezmien, 2018) and are identified later than Non-Latino White children (Magaña et al., 2013, Mandell et al., 2002). Furthermore, children from CLD communities receive later and less ASD services (Feinberg et al., 2011; Liptak et al., 2008; Magaña et al., 2013; Parish et al., 2012; Zuckerman et al., 2017). Understanding what CLD parents use to obtain information on ASD and how to present this information may be important for offsetting these disparities.

This research is particularly warranted for the Hmong community— a Southeast Asian refugee group with a U.S. population of approximately 310,000 and one of the fastest-growing ethnic groups in the U.S. (Asian American Center for Advancing Justice, 2015). The first Hmong families arrived in the U.S. in 1975 after Laos fell to communist forces during the Vietnam War. A second wave of approximately 15,000 Hmong refugees arrived in the U.S. in 2004 after the closing of Wat Thamkrabok, a Buddhist temple compound that housed Hmong refugees who did not want to relocate to another country post-war (Minnesota Historical Society, n.d.; Public Broadcast Station, n.d.).

4.1.2 Information-Seeking Challenges

Very few studies (across published studies and gray literature) have examined the information sources used by the Hmong community for other disability and health-related concerns. These studies reveal that the internet, doctors, teachers, books, television, radio, and friends and family are commonly-used sources (Harrison et al., 2007; Thao, 2010; Thorburn et al., 2013; Vang, 2015). To date, no studies have examined the information-seeking behaviors of Hmong parents specific to ASD. The Hmong community today faces three unique circumstances that warrant special attention as it relates to research on information-seeking behaviors.

4.1.2.1 Socioeconomic Factors

A number of socioeconomic factors potentially affect the information-seeking behaviors of Hmong parents. In comparison to the general U.S. population, the Hmong community is more likely to live in poverty, to rely on public assistance programs, to have lower educational attainment, and to have public versus private health insurance (American Community Survey, 2017). Such factors may limit Hmong parents' access to certain information sources (e.g., Hmong families living in poverty may have less access to doctors, the internet, or books). Mackintosh et al., (2005) found that families with lower household incomes used fewer sources of information to learn about ASD than families with higher incomes.

4.1.2.2 Cultural Factors

A number of cultural factors may also influence where and how Hmong parents seek ASD information. One such factor is stigma and shame surrounding ASD. Hmong parents in a qualitative study conducted by MDH (2014) shared the perception that parents of autistic children could be blamed for their child's ASD. Additionally, 57% of Hmong parents from Study 2 reported that ASD was seen as a "bad" thing in the community. Such perceptions could mean that Hmong parents are less likely to seek information about ASD from friends, parents of autistic children, and family members. Alternatively, it could also be that Hmong parents are more likely to seek information from family members (e.g., particularly grandparents, other elders, male family members), given that many families operate within a tight-knit clan structure where seniority (predominantly based on age) and patriarchy influence family functioning. Furthermore, many Hmong families believe in animism and practice shaman rituals. MDH (2014) found that spiritual conflicts (e.g., child's lost soul, child's name) were sometimes perceived to be the cause of ASD. For these families, shamans could be a valuable information source. A lack of trust of professionals is also a concern and could mean that Hmong parents are less likely to turn to doctors and other service providers for information on ASD. Parents perceived that doctors and other service providers ignored, disrespected, withheld information, or failed to follow up on their calls as a result of race or language (MDH, 2014). Finally, Hmong parents reported that there is no word for ASD in the Hmong language, making conversations about ASD difficult to have (MDH, 2014). Indeed, 66% of Hmong parents in Study 2 indicated that ASD was not talked about in the Hmong community. Low ASD visibility could make it difficult for Hmong parents to recognize ASD and seek ASD information altogether.

4.1.2.3 Linguistic Challenges

Text is one of the main ways ASD information is conveyed to parents. Frequently-used sources such as books, research articles, newsletters, and web pages are text-based (e.g., Mackintosh et al., 2005). Additionally, providing text in different languages, usually as translations of English text, continues to be one of the most commonly offered solutions when trying to address information and language challenges with CLD communities in healthcare and educational settings (Colina et al., 2004; Lo & Wu, 2009). This is problematic as the Hmong language has historically been oral with a relatively young history of literacy. Written Hmong had never existed for Hmong living in China, Vietnam, Laos, and Thailand, historically (Duffy, 2000). The Hmong writing system was only recently developed in 1952 by French and American missionaries using the Romanized Popular Alphabet (McGinn, 1989). Indeed, studies conducted in the 1980s and more recently continue to show low Hmong literacy (i.e., limited ability to read and write in Hmong). For example, Weslander and Stephany (1983) found that 63% of Hmong students could not read in their first language in comparison to 30% of Vietnamese students. These findings are not surprising given the lack of formal Hmong education and growing up with parents who also have low Hmong literacy (Kang et al. 1996). As more and more Hmong children are born in the U.S. and are exposed to English from birth, low Hmong literacy is likely exacerbated today (Vang, 2005).

Looking at census data from 1980 to 2000, Carroll (2021) found that English proficiency among younger Hmong generations is increasing. Less than 10% of the 1.5-generation-Hmong individuals (those born abroad who grew up in the U.S.) reported low English proficiency with only ~1% of 2nd-generation-Hmong individuals (those born in the U.S.) reporting low English proficiency, suggesting that the need for English language support (i.e., information provided in Hmong including Hmong text) has diminished. This finding, however, is somewhat conflicting with other studies. Vang

(1999, as cited in Vang, 2005) noted that many Hmong students were proficient in neither Hmong nor English. The American Community Survey ([ACS], 2017) also reported that Hmong individuals are still more likely to be English language learners.

As the students in the studies above become parents today, low Hmong literacy and varied English proficiency bring into question how warranted Hmong text is in sharing information on ASD (Allen et al. 2004). Is the tendency to provide Hmong text materials addressing a meaningful need? Or is the degree of its popularity being sustained by bias as speakers of languages like English with longstanding and ingrained histories of writing and reading? Tuffnell et al. (1994) found that when literacy is low in a target community, text documents, even when translated, are ineffective for sharing information and suggested alternative methods such as audio or video recordings. Allen et al. (2004) and Harrison et al. (2007) have indicated that audiovisual methods (e.g., television, radio, or video) are more preferable to text methods for disseminating health and educational information to the Hmong community. To ensure that Hmong text does not preclude consideration of or take resources away from more effective ways of sharing information, more research examining the need for Hmong text versus alternative methods for Hmong parents are required.

4.1.3 Purpose

Given the Hmong community's unique combination of socioeconomic, cultural, and linguistic circumstances, (1) it is unclear how the information sources Hmong parents use to learn about ASD compare to those identified in previous literature and (2) little is known about the necessity of Hmong text, despite language-specific text being frequently offered as a solution to linguistic challenges. This knowledge has important implications. First, there is reason to think the information sources Hmong parents use may differ. Magaña et al. (2013) found that Latino parents were significantly less likely than Non-Latino White parents to learn about ASD from the internet, books, magazines, healthcare professionals, friends, and other parents of autistic children. Secondly, this knowledge may inform efforts to improve disparities in ASD identification and the receipt of services. Specifically, putting helpful and accurate information about ASD (e.g., early signs of ASD, reasons for seeking an identification, how to start the identification process, the services available, reasons for seeking services, how to obtain services) in the places that Hmong parents often turn to for information may help with earlier identification and receipt of services for Hmong children.

Thus, this study addresses three research questions:

1. What sources do Hmong parents use to obtain information on ASD?;
2. Does the number of information sources Hmong parents report using predict age of ASD identification?; and
3. What is the extent to which Hmong parents encounter and utilize ASD information presented in Hmong text and audio?

4.2 Methods

4.2.1 Participants

The participants in this study were the same as those from Study 2, which included a total of 35 Hmong caregivers who were at least 18 years of age, residing in the U.S. and have a child with an ASD identification (i.e., a clinical diagnosis or eligibility for special education services under ASD) at the time of the study. Because data collection took place during the COVID-19 pandemic (mid October 2021 to February 2022), recruitment efforts were largely limited to online dissemination of the survey (e.g., social media postings, emails). As a result, the majority of participants were recruited via Facebook postings (*n* = 30, 85.7%). The survey could be completed online via Qualtrics ®, by paper, or through a one-on-one interview via Zoom for participants who required Hmong language support. One parent with limited English requested a one-on-one interview; all other parents completed the survey via Qualtrics ®. (Please see Study 2 for a detailed description of the recruitment process.) A $10 cash or Amazon gift card was provided as incentive to those who completed the survey. Written informed consent was obtained for all participants. For the participant who completed the survey via Zoom, a copy of the consent form was emailed prior to the meeting and was reviewed and completed at the beginning of the meeting before starting the survey. Study procedures were approved by the Institutional Review Board at the University of Minnesota.

On average, participants were 36.77 years old (SD = 5.54, Range = 27 - 47), most had at a postsecondary degree (n = 27, 77.1%), and a little more than half (n = 20, 57.1%) had a household income greater than $80,000. Most participants were from Minnesota (n = 16) and Wisconsin (n = 10), and most reported living in suburban and urban areas (n = 30). The children in this study were predominantly male (n = 30, 85.7%), with an average age of identification of 4.13 years (SD = 2.29, Range = 1.33 - 13). The first form of ASD identification was a clinical diagnosis for 20 children (57.1%) and an educational eligibility of ASD for 15 children (42.9%). Children who first received a clinical diagnosis were identified on average at 3.72 years of age (SD = 2.68, Range = 1.33 - 13.00), whereas children who first received an educational eligibility of ASD were identified on average at 4.67 years of age (SD = 1.57, Range = 2.5 - 7.5). This difference in age of identification was not significant, (1, N = 35) = 13.90, p = .606. Fifteen children (42.9%) were previously identified with a developmental delay, and eight (22.9%) also had an intellectual disability. (Participant characteristics are presented in Table 4.)

4.2.2 Measure

I developed the Parent Perceptions of Autism Spectrum Disorder (PP-ASD) survey to gather parents' knowledge and beliefs surrounding ASD (i.e., their beliefs about early identification, intervention, and the causes of ASD), the barriers and facilitators they encountered to getting their child identified, and the sources parents use to access information on ASD. The PP-ASD was informed by the available ASD literature as well as findings from a systematic review of parent-reported barriers and facilitators to ASD identification (Study 1) and was created on Qualtrics ® using survey guidelines from Halaydna and Rodriguez (2013) and Dillman et al. (2014). The PP-ASD was piloted with a convenience sample of parents of autistic children from a university research registry (*N* = 114) and was recently used with a community sample in Chaxiong (2020; *N* = 205). To ensure that the PP-ASD was appropriate for use with Hmong parents, I conducted three one-on-one virtual think-alouds with two Hmong mothers and one Hmong father of autistic children ages 3 through 24. (Please see Study 2 for a detailed description of the think-alouds and the following modifications to the PP-ASD.)

This study utilized the data on information sources from the PP-ASD. Participants were asked to select the sources they use to get information on ASD. This list included 25 different information sources compiled from previous studies (Gibson & Kaplan, 2015; Gibson et al., 2017; Grant et al., 2016; Mackintosh et al., 2005; Magaña et al., 2013, MDH, 2014), the pilot study of the PP-ASD, and the think-alouds with Hmong parents. The PP-ASD also asked participants to indicate how often they see and use ASD information presented in Hmong text and audio. Hmong text refers to written ASD information presented in sources such as books, newsletters, brochures, posters, flyers, or Facebook posts. Hmong audio refers to oral ASD information presented in sources such as radio shows, TV shows, videos/movies, and podcasts. (The PP-ASD can be viewed at https://z.umn.edu/Chaxiong_PP-ASD.)

4.2.3 Statistical Analysis

Descriptive statistics (i.e., means, percentages) were used to answer Aims 1 and 3. To identify information sources with the highest potential for reaching Hmong parents, prominently-reported information sources were highlighted, defined as those reported by >50% of Hmong parents. Aim 2 was addressed using a simple linear regression with number of information sources predicting age of first ASD identification. It was hypothesized that number of information sources would negatively predict age of identification. The interquartile range (IQR) technique was used to identify outliers, defined as data points that exceed the first and third quartiles by 1.5xIQR. One predictor observation (x = 25) and one outcome observation (x = 13) were eliminated based on this technique. Density and scatter plots of residuals indicated that assumptions for conducting regressions (i.e., normality, linearity, and homoscedasticity) were tenable. All analyses were conducted in the R software (R Core Team, 2019).

4.3 Results

4.3.1 Information Sources Used

Overall, participants reported using a variety of people-, online-, and text-based information sources to learn about ASD. A list of the 25 information sources are presented in Table 8. All but one source (Tumblr) were endorsed by at least one participant. Prominently-reported sources (i.e., those endorsed by >50% of participants) were internet search engines (Google, Yahoo, Wikipedia; 97.1%), doctors/healthcare professionals (91.4%), research articles (85.7%), other parents of autistic children (80.0%), teachers (74.3%), books (68.6%), autistic individuals (62.9%), and Facebook (60.0%). The sources that were least endorsed by participants were Twitter (2.9%), Reddit (2.9%), Pinterest (8.6%), and radio (8.6%). Other information sources shared by participants included current service providers, participant's own educational training, federal and state department websites (CDC.gov, health.state.mn.us), ASD support groups, and Tiktok.

4.3.2 Number of Information Sources as a Predictor of Age of Identification

On average, participants reported using 10.22 different sources for information on ASD (SD = 4.24, Range = 3 - 19). Results from the simple linear regression indicated that the number of information sources participants reported using (β = 0.20, p = .001) was a significant predictor of the age of their child's first ASD identification, R^2 = .27, F(1,

31) = 12.82, *p* = .001, 95% CI [0.09, 0.32]. Specifically, for every additional information source participants used to obtain ASD information, there was a corresponding .20 year (~2.5 months) increase in the age at which their child was identified for ASD.

4.3.3 Availability and Usage of ASD Information Presented in Hmong

Overall, study results revealed that the majority of participants did not encounter or use information on ASD presented in Hmong. Results are presented in Table 9. The majority of participants (82.9%) indicated never encountering ASD information presented in Hmong text. When asked how often participants use this information (when/if they come across them), 60% indicated that they never used them; however, 40% indicated that they did. Of these participants, 14.3% indicated always using the ASD information presented in Hmong text that they come across. Similarly, 74.3% of participants indicated never encountering ASD information presented in Hmong audio, although 20.0% and 5.7% indicated encountering this information some of the time and most of the time, respectively. When asked how often participants use this information (when/if they come across them), 54.3% indicated that they never used them, while 45.7% indicated that they did. Of these participants, 20% indicated always using the ASD information presented in Hmong audio that they come across.

4.4 Discussion

This study examined (1) the sources Hmong parents use to learn about ASD; (2) the relationship between number of information sources parents use and age of ASD identification; and (3) the extent to which Hmong parents encounter and use information about ASD provided in Hmong text and audio.

First, the findings demonstrate that Hmong parents seek ASD information from a variety of sources, and these sources are similar to those reported in previous studies of predominantly White, English-speaking families (Gibson et al., 2017; Mackintosh et al., 2005). Of note, this study found that 60% of Hmong parents turn to Facebook for information on ASD. In comparison to 8% of parents in Gibson et al. (2017), this study's finding is markedly higher. Given that the majority of participants in this study were recruited from Facebook, this high percentage is not all that surprising. It is also possible, however, that Hmong parents turn to Facebook for information more often than other parents or that, in general, the use of social media platforms like Facebook for information have tremendously increased in the last several years.

Since its inception, Facebook has expanded from serving as a social networking site to a source of news and information. Recently, Facebook has been used for sharing information on health topics such as the Zika virus (Sharma et al., 2017), breast cancer (Bender et al., 2011), teen depression (Lerman et al., 2017), and most recently COVID-19 (Syn, 2021) in addition to ASD (Abel et al., 2019; Mohd Roffeei et al., 2015). With nearly two billion users monthly— a majority of which are actively engaged in liking, commenting, posting, and sharing— Facebook is a potentially powerful tool for sharing ASD information (McClain, 2017). For communities with limited access and exposure to conventional sources like doctors, books, and research articles, the delivery of information via Facebook may be an advantageous alternative. The effectiveness of information-sharing via Facebook, however, remains unclear. Evaluation studies indicate that current Facebook groups do more for social support but focus less on delivering accurate information (Abel et al., 2019). Inaccurate, low credibility, and misleading posts are prolific and also seem to receive more attention than posts with accurate information (Sharma et al., 2017; Yang et al., 2021). More research is needed to examine the effective usage of Facebook and other social network sites such as Twitter, which the scientific community appears to more heavily favor (Collins et al., 2016).

This study also found that the number of information sources Hmong parents reported using predicted the age of their child's ASD identification, although in the opposite direction of the hypothesis. Specifically, the more sources parents reported using, the later their child's age of identification. It is possible that the longer an identification takes, the more time and motivation parents have to seek more information. This finding should be considered in light of the fact that the PP-ASD asked parents to indicate the sources they use to get information on ASD generally and did not specify for parents to report the sources they used in order to obtain an identification. Finding a relation between number of information sources and age of identification stands in contrast to Hrdlicka et al. (2016) who found no relation. This discrepancy may be due to differences in study populations and the number and variety of information sources used in each study. Hrdlicka et al. focused on European parents and provided a much more limited list of information sources focused largely on different healthcare and educational professionals, in addition to the internet, books, media, and families with shared experiences.

Finally, the results from this study suggest that information on ASD presented in Hmong, whether in text or audio form, is not prevalent and that the majority of Hmong parents did not require them. This finding is not surprising, given findings that English proficiency has significantly increased in the Hmong community over time (Carroll, 2021). Service providers who work with Hmong parents in the Minnesota area also observed that younger Hmong parents are fluent in English and that language was not an issue for service delivery (Her, 2015). It should be noted, however, that 40% and 45.7% of parents did report using the Hmong text and audio information they encountered, respectively— a significant minority— suggesting that ASD information presented in Hmong is being used and serves a purpose. The PP-ASD did not ask parents to indicate where they encountered Hmong text and audio information which would have provided important insight as to whether English and Hmong information on ASD are found in similar places. When compared, slightly more parents encountered Hmong audio information than Hmong text information and slightly more parents also indicated using Hmong audio information than Hmong text information, aligning with previous research that ASD information presented in Hmong audio may better reach Hmong parents (Allen et al., 2004; Harrison et al., 2007). It should be noted that these results do not reflect the preferences of all Hmong parents, given that participants in this study were fairly well educated with middle to high family incomes and only one participant indicated having limited English. It is clear more research is needed to examine the necessity of Hmong text and alternative ways of information-sharing with a more representative or purposive sample of Hmong parents.

This study in no way suggests that providing information in Hmong text be discontinued; however, consideration of historically low Hmong literacy presents, at the very least, reason to examine its need and other potentially effective ways of information-sharing. As previously discussed, text is one of the main ways ASD information is conveyed to parents, and providing text in different languages, usually as translations of English text, is a common go-to solution for addressing information barriers to CLD communities. Several issues pertaining to translated text are critical to consider. Few translation guidelines exist and few educational programs are available to teach translation pedagogy. This means much translated work has relied on bilingual speakers with little to no translation training (Colina et al., 2004). Not surprisingly, several studies have highlighted that important translated educational and medical documents have inadequately conveyed information from their original English versions. Colina et al. examined a number of translated educational documents (e.g., informational brochures, application forms, letters, and permission slips) used at the state and local levels by Arizona schools to inform Spanish-speaking parents and students of available programs and services. They found that the translated documents did not adequately convey the intentions of the original English versions. Lo and Wu (2009) found that Chinese-translated individualized education programs (IEPs) were missing critical information (e.g., duration of services, IEP objectives) and terms were mistranslated or so literally translated that they made little sense. Jhanwar and Bishnoi (2010) examined Hindi-translated informed consent forms for psychiatric clinical trials and found that they were too complex for the average Hindi reader. It is clear that good translation work requires time, money, and well-trained translators, making it crucial that we examine the need for Hmong-translated texts.

4.4.1 Limitations

This study has several limitations to consider. First, the findings come from a biased sample of Hmong parents. COVID-19 severely limited the number of ways participants could be recruited. As previously described, the majority of participants came from postings in disability, education, and ASD Facebook groups and pages. Parents who are a part of these groups may qualitatively differ from parents who are not. Additionally, given that only one participant required Hmong language support to complete the survey, this sample may not have been appropriate for learning about the need for Hmong text. Future studies with purposive sampling of Hmong parents with limited English proficiency (i.e., those who actually need or rely on ASD information presented in Hmong) may provide more accurate information on Hmong text and alternative ways of presenting information.

4.4.2 Conclusion

Overall, the Hmong parents in this study reported using a variety of sources to learn about ASD, similar to those reported from studies of predominantly White, English-speaking participants. The number of sources Hmong parents reported using was related to their child's age of ASD identification; specifically, the use of more sources was associated with later age of identification. Research with a more representative sample is needed to gain a more accurate picture of the information sources Hmong parents use. Finally, the majority of Hmong parents in this study reported infrequent encounters with and usage of ASD information presented in Hmong, whether it be in text or audio form; however, the nuances of this finding need further examination with a purposively-derived sample of Hmong parents. Improved knowledge of the information-seeking behaviors and preferences of Hmong parents may be useful in efforts to improve inequities in ASD identification and intervention but may also be helpful in efforts to educate Hmong parents about other prevalent health conditions such diabetes and depressive disorders.

Chapter 5: General Discussion and Conclusion

5.1 Overview

The literature on ASD suggests that (1) CLD children are more likely to receive late ASD identifications and (2) CLD parents may experience more challenges in the identification process, making steps towards an ASD identification more difficult. These findings are problematic as an early ASD identification is important for early access to crucial supports and intervention services for autistic individuals and their families. The Hmong community is one CLD group that is particularly vulnerable to inequities in ASD identification, yet very little ASD research has focused on this community. My three-study dissertation examines Hmong parents' beliefs about ASD and their experiences in the identification process to address the overarching question: *how can we enable Hmong parents to take steps towards an ASD identification?* Below, I summarize notable findings from each study that particularly inform this question.

Study 1 was a systematic review of qualitative and descriptive studies that examined parents' experiences in the identification process in the U.S. Barriers and facilitators to ASD identification reported by parents in these studies were compared to factors reported in Daniels & Mandell (2014) to predict age of identification. Prominently-reported barriers (e.g., "parent limited knowledge of ASD", "community stigma", "professionals' dismissal/normalization of parent concerns", family/friends' dismissal/normalization of parent concerns", "parent denial", "lengthy process and wait times", "professionals discrediting/devaluing parent insights"), prominently-reported facilitators (e.g., "parent persistence", "professionals who made referrals", "professionals who were attentive to parent concerns", supportive friends, family, and outside network), and the barriers (e.g., parent limited knowledge of ASD", "process involving many professionals") and facilitators (e.g., "parent knowledge of child development", "parent knowledge of/familiarity with navigating the identification process", "professionals who made referrals”) that overlap with factors that predict age of identification found in Daniels et al. underscore the importance of (1) ensuring parents have access to information on ASD and identification and (2) supporting healthcare and educational professionals to be proactive partners in the identification process.

Study 2 then focused specifically on Hmong parents’ beliefs related to ASD (i.e., their beliefs about early identification, intervention, and the causes of ASD) and their experiences in the identification process (i.e., the barriers and facilitators they encountered). The Hmong parents in this study reported being actively involved in their child’s identification process and holding beliefs about identification and intervention that facilitate steps towards identification. Additionally, the parents in this study reported encountering more facilitators than barriers. Prominently-reported barriers point to the need to address a lengthy and slow identification process (e.g., “I had to wait a long time before my child could get an appointment to be tested for autism”), as well as stigma and low ASD awareness (e.g., “autism is not talked about in the Hmong community”, “autism is seen as a bad thing in the Hmong community”). Prominently-reported facilitators highlight parent knowledge and actions (e.g., “I kept pushing and trying”, “I could speak and understand English”, “I tried to find my own information”, “I knew about child development”, “I knew about autism”) and helpful responses from healthcare and educational professionals (e.g., “doctors/teachers were knowledgeable about autism”, “doctors/teachers listened to my concerns”, “teachers encouraged me to get my child tested for autism”, “doctors referred me to someone who could test my child for autism”). Similar to Study 1, these findings suggest that equipping parents with the knowledge and means to move through a stressful, lengthy identification process can facilitate ASD identification. Furthermore, supporting healthcare and educational professionals to be proactive partners can help parents move towards ASD identification.

Because of the important theme of parent knowledge and access to information, Study 3 examined the sources Hmong parents use to obtain information on ASD as well as the extent to which they encounter and utilize ASD information presented in Hmong text and audio. The results indicated that internet search engines, doctors/healthcare professionals, research articles, other parents of autistic children, teachers, books, autistic individuals, and Facebook may be strategic places to present ASD information to reach Hmong parents. Although the majority of Hmong parents in this study reported not using ASD information presented in Hmong text or audio, a significant minority did (40% and 45.7%, respectively). ASD information presented in Hmong audio was slightly more prevalent and more utilized than ASD information presented in Hmong text, suggesting that audio information may better reach Hmong parents.

5.2 Implications

5.2.1 Ensuring Access to Information for Parents

Altogether, findings from Studies 1 and 2 substantiate parents as key stakeholders to involve in efforts to promote earlier ASD identification. In other words, asking how we can enable parents to move towards an ASD identification (as was done in this dissertation) is a socially-meaningful approach to addressing the issue of delayed ASD identification. Specifically, these two studies reveal that ensuring parents have access to information on ASD may be one way to enable parents towards an ASD identification. The literature suggests that helpful information include the early signs of ASD, reasons for seeking an identification, how to start the identification process, reasons for seeking intervention, the services available, and how to obtain services. Being informed can help parents overcome notable barriers such as community stigma, limited public awareness of ASD, parent denial, dismissal of concerns from healthcare providers and educators, and a complicated and lengthy identification process, which in turn may enable parents to be more persistent– an important facilitator.

Findings from Study 3 suggest a number of ways to help Hmong parents learn important information about ASD. As reviewed above, healthcare providers, educators, autistic individuals, and parents of autistic children are important disseminators of ASD information for Hmong parents, in addition to the internet, Facebook, books, and research articles. Creative ways to disseminate ASD information that integrate multiple information sources used by Hmong parents may be particularly advantageous. One example of such efforts are Facebook groups like Supporting all Abilities Welcoming all Voices and Ua Tau. These groups (a) utilize the internet and Facebook as platforms; (b) connect parents, board certified behavior analysts, teachers, parent advocates, school psychologists, social workers, speech language pathologists, and occupational therapists; (c) present ASD information in Hmong and English and in a variety of forms including text, pictures, videos, and Facebook live streams; and (d) describe research findings in culturally accessible ways. These groups are particularly efficient in that by joining them, parents gain access to a number of different information sources that they do not need to individually seek. More research, however, on the effectiveness of these groups and their reach/membership are needed.

5.2.2 Supporting Healthcare and Educational Professionals to Serve as Partners

Studies 1 and 2 indicate that healthcare and educational professionals play key roles in parents' abilities to move towards an ASD identification. Study 2 suggests that educational professionals may be more supportive partners than healthcare professionals for Hmong parents in the identification process. Hmong parents reported more barriers pertaining to doctors and more facilitators pertaining to teachers. Although healthcare and educational professionals are both uniquely positioned to contribute significantly to the early identification of ASD, a number of technical, personal, and system challenges (described in Study 1) prevent them from serving as proactive partners for parents in the identification process. It is clear that solutions beyond providing healthcare and educational professionals with ASD training are needed. Research examining their experiences providing ASD screening and assessment may inform how healthcare and educational practices can be more conducive to the identification of ASD and other concerns. This may help to alleviate a number of parent-reported barriers such as dismissal/normalization of parent concerns and lack of trust and could also help healthcare and educational professionals voice concerns, recommend evaluations, and make referrals– all notable facilitators reported by parents.

5.2.3 Considerations

The two large recommendations that come from this dissertation are based on examination of parents' experiences in the identification process, and thus reflect what parents see hinder or support their steps towards an ASD identification. It is likely that different recommendations would arise with healthcare providers, educators, ASD specialists, and policy makers as the focal population or when aspects of the identification process are analyzed (e.g., how many identification services are available per county?; how many providers are involved in an ASD identification?; how long are wait times for an evaluation?; how much do screenings and evaluations cost?; how are providers compensated?). For example, although screeners are not often conducted and the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F)— the most widely used ASD screener— has lower specificity and positive predictive value in Black, Asian, and multiracial children and children with non-English exposure (Guthrie et al., 2019), better screening practices and tools did not rise as a prominent issue needing to be addressed in order to help parents move towards an ASD identification. Better screening tools, however, may arise as a prominent need for early ASD identification from the perspectives of healthcare providers.

5.3 Limitations and Future Directions

This dissertation has several limitations. In all three studies, data was based on parent report. In Studies 1 and 2, it is possible that what parents report are barriers and facilitators in the identification process do not actually affect age of identification. Children's ASD identifications in Studies 2 and 3 were also based on parent report and were not independently verified. Relatedly, the PP-ASD, used in Studies 2 and 3, is a retrospective survey and relies on parent recall which is susceptible to errors such as reduced accuracy and change in thinking (Ozonoff et al., 2018). Although other literature, think-alouds with parents, and a pilot study also informed the development of the PP-ASD, it was largely informed by findings from Study 1. Thus, Studies 2 and 3 may be limited by the conclusions drawn from Study 1. Additionally, COVID-19 severely limited the number of ways participants could be recruited for Studies 2 and 3. This not only limited the sample size but may have also led to a biased sample. The majority of participants came from postings in disability, education, and ASD Facebook groups and pages. Parents who are a part of these groups may qualitatively differ from parents who are not. Furthermore, the sample was fairly well educated with middle to high household incomes. Findings from Studies 2 and 3 should be considered in light of these participant characteristics. Moving forward, findings from Study 2 should be followed with a larger and more representative sample of Hmong parents, especially for understanding the exploratory analyses of potential predictors of age of identification that yielded unexpected results. Because Study 3 examined the need for information on ASD presented in Hmong, purposive sampling of Hmong parents with limited English proficiency (i.e., those who actually need or rely on ASD information presented in Hmong) may provide more accurate information.

5.4 Conclusion

My three-study dissertation examined Hmong parents' beliefs about ASD and their experiences in the identification process to address the overarching question: *how* *can we enable Hmong parents to take steps towards an ASD identification?* In summary, these studies point to the importance of ensuring that Hmong parents have access to information on ASD and that healthcare and educational professionals be supported to serve as partners.

Table 1
Study Characteristics

Study	Methodology		Participant Description				
	Relevant research/survey/ interview question(s)	Design Approach; Analysis method; Measure(s)	 N Female Male Age	Education HS/less College Grad/Prof	Income	Location	Race/Ethnicity Asian Black/Afr. Am. Hawaiian/Pacific Latino/Hispanic Native Am. White Multiracial Other/NR
1. Coffield et al. (2021)	"The goal of this study was to develop a deeper understanding of the period from identification of initial developmental concerns to receipt of diagnosis from the perspective of Latino parents using qualitative methods."	Qualitative; Constant comparative method; Interview	21 20 1 NR	18 2 0	NR	NR	0 0 0 20 0 0 0
2. Crais et al. (2020)	"What helped and what were barriers in moving toward getting an ASD diagnosis for your child?"	Qualitative; Grounded theory; Focus group	55 NR NR NR	NR	NR	Eastern, Western, Central NC; 34 lived in urban	1 3 0 18 9 42

						counties; 21 lived in rural counties	0 0
3. Dababnah et al. (2018)	"What barriers and facilitators do parents and other caregivers of Black children experience regarding ASD screening in primary healthcare settings and subsequent referral to specialty care, such as comprehensive developmental evaluations?"	Qualitative; Grounded theory; Interview	22 22 0 NR	10 6 5	<25k: 6 25-49k: 4 50-74,999: 4 75-99k: 3 100k: 5	Baltimore, MD	0 20 0 1 0 1 0 0
4. Elder et al. (2016)	"Do you think there are barriers that keep children who have ASD from being diagnosed as soon as they could be? If so, what are those? If so, what would help these diagnoses happen sooner?"	Qualitative; Analytic coding; Focus group	35* NR NR 22-68	NR	NR	FL; rural, remote areas	0 1 0 0 0 34 0 0
5. Hidalgo et al. (2015)	"The third question asked caregivers to describe whether there were any barriers to earlier identification/diagnosis."	Multi-method; Thematic analysis, descriptive analysis; Questionnaire, interview	54 46 8 NR	31 0 0	24.1% at/below poverty level	Northwest, US	2 3 (or multiracial) 0 6 0 35 0 0

6. Jegathee- san et al. (2010)	“The interview topics centered around four areas: diagnosis and parental reactions, parent perspectives regarding the etiology and treatment, parents’ experiences with professionals, and efforts to obtain appropriate services.”	Qualitative; Ethnography; Interview, field observations	6 3 3 30s-40s	NR	Low - middle SES	Midwest, US; urban city	6 0 0 0 0 0 0 0
7. Johnson et al. (2020)	“The purpose of this study was to explore the experience of accessing autism diagnosis and resources in a Midwest urban public school district for diverse mothers of children with ASD.”	Qualitative; Narrative inquiry method; Focus group	9 9 0 NR**	5 2 2	<$61,000	Midwest, US, urban public school district	0 5 0 2 0 2 0 0
8. Kalash et al. (2012)	“Describe the process of how your child became diagnosed with an autism spectrum disorder.”	Qualitative; Phenomeno-logical; Interview; field observations	12 8 4 NR	NR	NR	Midwest, US	NR
9. Lappé et al. (2018)	“...to analyze how parents of children with autism experience ASD diagnosis and their perceptions of the individual, social, and structural factors that influence this process.”	Qualitative; Grounded theory; Interview	44 22 22 M=37.9	18 16 10	<10k: 1 10-20k: 1 20-30k: 3 30-40k: 2 40-50k: 1 60-80k: 5 80-100k: 1 >100k: 7	Los Angeles, CA	10 7 2 12 2 14 0 5

10. Moodie-Dyer et al. (2014)	“When and how was your child diagnosed with an ASD and what was this experience like for you and your family?”	Qualitative; Content analysis; Interview	19 18 1 NR	NR	NR	Midwest, US	NR
11. Narcissa et al. (2012)	“The first portion of the survey focused on parental perceptions regarding the ASD diagnostic process related to the respondent’s most recently diagnosed child...Additional questions explored the reasons for perceived delays in the diagnostic process and parental anxiety levels prior to their child receiving an ASD diagnosis.”	Descriptive; Descriptive analysis; Survey	162 144 18 NR**	23.5% 39.6% 36.9%	<25k: 5.9% 25-50k: 18.5% 50-75k: 17.6% 75-100k: 21% >100k: 37%	24 states	0 7.2% 0 5.7% 0 84.2% 2.9% 0
12. Pearson et al. (2018)	“What are the reported experiences of African American parents of children with ASD in grades K-5 when obtaining an initial diagnosis?”	Qualitative; Constant comparative method; Interview	11 11 0 M=38.9	3 5 3	8.7k-90k M = 48,605	Midwest, US; urban and rural	0 11 0 0 0 0 0 0
13. Sakai et al. (2019)	“This study sought to identify barriers and facilitators to the identification and management of autism among Chinese immigrant children and	Qualitative; Modified grounded theory; Interview	16 14 2 NR	12 4 See college	NR	Northeast; US	16 0 0 0 0 0

	recommendations for improving the current system of care.”						0 0
14. Sansosti et al. (2012)	“Tell me about the barriers to receiving an earlier diagnosis.”	Multi-method; Grounded theory, correlational analysis; Interview, quantitative measures	16 13 3 31-35	4 12 See college	85k-99k	OH	0 4 0 0 0 10 2 0
15. Stahmer et al. (2019)	“What and who was helpful in finally getting a diagnosis? What got in the way of getting a diagnosis?”	Qualitative; Thematic analysis; Focus group	58 50 6 M=37.1	NR	<30k: 23 30-49,999: 15 50-69,999: 12 70k+: 7	Sacra-mento, CA; Los Angeles, CA; Rochester, NY; Philadel-phia, PA; urban and rural	14 18 0 26 0 0 0 0
16. Wong et al. (2017)	“In your own words, please describe the process you and your family went through to receive a diagnosis of an ASD in your child.”	Multi-method; Thematic analysis, descriptive and correlational analysis; Quantitative questionnaire w/	78 98.7% 1.3% M=35	67% 33% 0%	<60k: 59%	IN	0 0 0 0 0 94.9% 0 5.1%

		open-ended responses					
17. Zucker-man et al. (2017)	"Think back about the period before a doctor diagnosed your child with ASD"; participants were also asked to indicate their agreement on a 4-part scale to specific barriers.	Descriptive; Descriptive and correlational analysis; Survey	352 316 27 NR	13.7 years of schooling	NR	CA, CO, OR	0 0 0 189 0 163 0 0
18. Zucker-man et al. (2014)	Interview guide asked participants about "barriers experienced before and during the ASD diagnostic process".	Qualitative; Thematic analysis; Focus group, interview	32 24 8 M=32	Years of schooling: Spanish-speaking: 8 English-speaking: 12	NR	OR; urban and rural	0 0 0 31 0 0 0 1

Note.
**N* includes caregivers/other family members, healthcare providers, educators, other service providers.
**Age of participants was reported as age brackets and could not be feasibly summarized here.
NR = Not reported.

Table 2
Parent-reported Barriers to ASD Identification

Barriers	Excerpts
Limited knowledge	
Professional limited knowledge of ASD S2, S4, S12, S14, S17, S18	S12: *The first pediatrician we had, she was just a general practitioner. She is like, 'I really don't know anything about it [autism]'. I would come to her and tell her different things and she was just like, 'I really don't know anything about it'* (p. 25). S14: The majority of participants' comments revealed concerns that professionals were uninformed about or lacked sufficient training in ASD. Specifically, many participants felt that professionals appeared not to understand the effectiveness and necessity of early identification (p. 87).
*Parent limited knowledge of ASD S2, S7, S4, S5, S12, S13, S16, S17, S18	S5: ...They [parents] did not know what to look for or the kinds of questions to ask their doctor (p. 151). S18: Many [Latino parents] said that they knew little or nothing about ASD before their child's diagnosis (p. 303).
Parent limited knowledge of child development S9, S12, S15	S9: These participants often did not initially view their child's development as warranting medical attention...These parents and others we interviewed initially interpreted their children's behaviors as normal deviations from expected developmental milestones or reflections of their unique personalities (p. S275). S12: Mothers admitted that they knew little about development and disability...some mothers knew something was different about their child, but they were not exactly confident in their knowledge of the characteristics of disability (p. 24).
Low public/community awareness of ASD S5, S18	S18: Nearly all parents felt that there was little knowledge about ASD in the Latino community and that lack of knowledge impeded early ASD identification (p. 303).
Community stigma S2, S3, S4, S5, S13, S15, S18	S4: *If [other parents] have a child with autism, you can talk to them but other than that it's still hush-hush 'we don't talk about this kind of thing'...it's still a stigma and it's still hard to talk to your buddies about* (p. 415).

	S15: They [parents] described the process of finding out about their child's disability as a "*trauma*" and used words such as "*shocking*" and "*painful*" (p. 765).
Dismissal of parent concerns	
Professionals' dismissal/normalization of parent concerns S1, S2, S3, S4, S5, S7, S8, S9, S10, S11, S12, S14, S15, S17, S18	S2: For most caregivers who raised a concern with their physician, reassuring language was often used (e.g., *"He'll talk when he's ready"; "He's fine, don't worry"*). Some negated caregiver's concerns, *"I think you're looking for something that's not there*," or in a perceived condescending tone, "*He passed the MCHAT at 2, so what makes you think he has autism?*" Some professionals told caregivers they were sure the child did not have ASD, thereby delaying diagnosis (p. 249). S14: An overwhelming majority of the participants indicated that they were told to wait until their child was older. Most often (85%), participants indicated that pediatricians and other early child care providers told families that their child would *"grow out of it"* or that it was *"too early to look at autism."* One parent stated that she was told, *"come back when your child is older and his behavior is more under control...because [his] behavior was bad and our parenting was [perceived as] not matching my son's needs"* (p. 87).
Family/friends' dismissal/normalization of parent concerns S2, S6, S8, S9, S12, S13, S15, S17, S18	S2: *There's no family support, like my husband. I bet everyone else has the same story. Husbands don't know about any of this* *until their kids can't participate on a soccer field [others say "yes" or "amen" in agreement] because they're working and don't see it* (p. 250). A few felt their husbands had delayed their child's diagnosis and others felt unsupported by family and friends (p. 251). S17: Family members/elders [not] thinking child's behavior was problematic; spouse/partner thinking child's behavior [was] not problematic (p. 6).
Parent denial S2, S3, S5, S9, S12, S13, S17, S18	S3: Several participants asserted that denial or shame related to having a child with special needs is prevalent in the Black community, which reduced awareness of ASD...Another mother with a graduate degree asserted denial and the fear of ''labeling'' a child with special needs might delay some parents from seeking assistance when healthcare providers or others expressed concerns about their child's development (p. 329).

Challenging conditions of the identification process	
Evaluations being uncomfortable for child S17, S18	S18: Given that many children with ASD have challenges with sensory issues, changes in their routine, and interacting with strangers, ASD diagnostic evaluations were often unpleasant for the child. This was particularly the case for families who had to come for multiple visits. These factors may have made parents reluctant to follow up after an initial experience, especially if that experience was a negative one (p. 305).
Confusing/stressful process S12, S13, S15, S17, S18	S13: *You don't know what to do or how to do it? You don't know who to talk to. The doctor referred me but did not give me an appointment. The system is too hard. I called and they told me I had to wait half a year because there are so many people. They told me I had to fill out a form in order to receive a first appointment. The form was all in English, and I did not know what to do* (p. 5).
Lengthy process and wait times S2, S9, S10, S11, S13, S15, S16, S17, S18	S16: ...Many other parents mentioned that the diagnostic process was very lengthy. Parents reported three main hurdles to obtaining a diagnosis—wait time to get the first appointment *("After only 6 months on the waiting list we were able to get an appointment with a developmental pediatrician")*, lengthy diagnostic evaluation and testing procedures *("Lots of tests. Took a year and a half. Starting with inconclusive hearing testing...Then went to interviews, MRI, EEG, and DNA tests for fragile X, lead testing. Final piece was a non-verbal child test for autism.")* and wait time to get evaluation results/diagnosis or for professionals to agree to a final diagnosis *("It was a living nightmare because we could not get all professionals involved to agree on the Autism diagnosis")* (p. 204).
*Process involving many professionals S2, S6, S8, S10, S16, 18	S18: *The most difficult part was the fact that I was sent to so many different specialists. And the specialist will only look at one piece of a puzzle; they just don't put everything together. And that's what I found mostly, is that the time between seeing different people was a long time. So that made it really, really difficult to be able to get any kind of answers and any kind of help for [child]* (p. 305).
A shortage of evaluation services and professionals S2, S11, S15	S2: Other cultural barriers included limited information and availability of services in their communities. For some American Indian caregivers, resources were not viewed as high quality. In addition, some noted seeking support outside the tribal community was seen as unnecessary: *"[We're] from a community*

	where we are considered a country within a country…where everything is isolated” (p. 251). S15: *There are programs, but I don’t feel we should have to go to (close by city) or out of our immediate [area] in order to get the help for our kids. That’s not fair* (p. 764).
Shortcomings of screening and diagnostic tools/procedures	
Inadequate screening procedures/tools S2, S4, S5, S13	S2: *“He passed the MCHAT at 2, so what makes you think he has autism?”* (p. 249). S4: *I think most of the doctors that saw my kids only asked me five questions. And like that’s not really giving you a big enough picture* (p. 415). *...at her 18-month checkup, we had to fill out the form and I thought there could still be a lot of reason to have concern and still be able to say yes or no to all of these questions. It’s—they try to catch the upper threshold of the spectrum. The questions are more skewed to the more severe (p. 415).*
*Misidentification S2, S8, S15	S2: In contrast, some caregivers were initially told the child did not have ASD. Some saw multiple providers and received varied diagnoses (e.g., language, developmental, behavioral, or sensory processing conditions) before an ASD diagnosis (p. 249). Caregivers also reported some professional’s hesitance to diagnose ASD: *“I had to chase the diagnosis. They want to label him as developmental delay. They do not want to label autism* (p. 249). S15: Many families experienced initial misdiagnosis although reasons for this varied across groups. For example, speech and global developmental delays were more commonly reported by Korean and Hispanic/Latino caregivers, whereas Black caregivers uniquely reported ADHD and other externalizing disorders as the first diagnosis they received (p. 763).
Child not meeting ASD criteria S11	S11: [Child] did not meet ASD criteria (p. 142).
Negative professional-parent interactions	
Poor communication between professionals and parents	S5: In one instance, the parents said they later found the doctor had written some concerns in their child’s chart, but

S5, S7, S13, S15, S16	did not mention them to the parents until much later. Many families voiced a need for more open communication between parents and doctors, and for doctors to listen to parents' concerns (p. 151). S7: *Not once did they ever mention autism. They said he's developmentally delayed. I need you to come in to an IEP meeting and sign off on this. I said no. Nothing was really explained* (p. 260).
Professionals discrediting/devaluing parent insights S2, S6, S8, S10, S14, S15, S16	S14: ...Professionals, at times, did not share parents' concerns and did not use the information that parents provided in a collaborative nature...Several families commented that there appeared to be an *"unwillingness to acknowledge parents might know something"* about autism (p. 87). S16: ...Some parents felt insulted *("He was the rudest person I have ever met")* or ignored by professionals during medical consultation sessions *("First, we had to convince the pediatrician that there was something very wrong, which took 3 visits—4–5 months—before he took us seriously. In the end he was irritated by us.")* (p. 204).
Parents not trusting professionals S3, S13, S16, S17, S18	S18: Most parents trusted providers throughout the diagnostic process; this was particularly the case in Spanish-language focus groups. However, as the process stretched out over time, parents became frustrated. Some began to doubt whether providers were acting in their child's best interest. One parent suggested that perhaps providers were deliberately making services difficult to access for Latinos in order to save money. Another felt that her ASD diagnostic visit was mainly for conducting autism research rather than for diagnosing her child. Because providers' diagnoses and recommendations seemed less trustworthy, some parents may have put off acting on these recommendations (p. 306).
Parents perceiving racism/racial bias from professionals S3, S15, S18	S3: ...Several caregivers discussed specific instances when they perceived racism led to their primary healthcare providers to make negative assumptions about them or their families. Participants reported these assumptions disrupted the caregiver-provider partnership, creating a barrier to ASD screening (p. 329).
Cultural disconnect between professionals and parents S6, S12	S6: ...Parents reported that European-American doctors tended to be very straightforward and time conscious, spending less time interacting with them and showing little or

	no interest in their general background. The parents found this to be very distancing and cold (p. 804).
Language barriers (limited English proficiency)	
Language barriers preventing scheduling and attending appointments S13, S15, S18	S15: *We could have gotten the diagnosis earlier because [our son] had some complications at birth [...] the pediatrician told us to come in every six months [...] for six months he asked us to come but we did not. We went exactly once and then never again [...] I do not even know English so I wasn't in a condition to go there by myself. I could not go* (p. 759). S18: Language issues made scheduling appointments...particularly difficult (p. 304).
Language barriers limiting access to professionals and services S2, S15	S15: *We want to find Korean professionals because we cannot speak English. If we need to find a doctor, for example a psychiatrist, we would get referrals from our friends, and finally get connected to a Korean doctor. But it all comes down to this. 'I will see your child so give me $500 per hour.' Or 'for an hour, give me this much.' Stuff like this needs to stop... but we still go to them because we have no other choice* (p. 760).
Unavailable or poor interpretation services S17, S18	S18: Poor interpreter access or quality also made it difficult for parents to express their concerns and navigate the diagnostic process (p. 304).
Language barriers limiting access to information S2, S13, S15	S13: *When I go on the Internet to look up things, very little is in Chinese. It is all English. So I need to use the dictionary. There is a lot of information all in English. Even in public places, all the information is in English. For new immigrants, I cannot understand this. They should translate everything to Chinese* (p. 5). *Language, I think language is an issue. You hope the doctor would give you more information [about autism] and explain it. But, even if the words are very clear, we might still not understand. That is because we have different backgrounds. It is so hard to understand what is going on* (p. 5).
Language barriers preventing parent advocacy and communication of concerns S13, S15	S13: *I took my child to the family doctor and told him about his behaviors and what my worries were. But I could not really express myself because of the language. I think the families could really use a lot of help* (p. 5). S15: *If I could speak English well, I could have pushed but I could not. Actually I am pretty good at arguing in Korean, but*

	when it's in English I cannot...You have to know the language in order to fight well [laughs] in order to get services (p. 760).
Language complicating child's identification S1, S15, S17	S1: *And they said "No, it's normal for the two languages that he is processing, nothing is wrong with him" and so every time, until one day I said, "no, not anymore. Every time I come here you tell me the same thing. I need that he see a specialist…* (p. 713). S15: They [participants] thought that the diagnosis was delayed, at least in part, due to caregivers and providers attributing child language delays to limited exposure to English (p. 764).
Limited personal/family resources	
Lack of childcare S17, S18	S17: [No] help with care coordination (p. 6). S18: Lack of money for...child care made appointments harder to schedule (p. 305).
Work and time constraints S5, S18	S5: Lastly, 7% of families (n = 3) said lack of time was a barrier given the time needed to seek out medical and diagnostic evaluation appointments (p. 151). S18: Some parents worked multiple poorly paying jobs, in temporary or seasonal work, with no flexibility to take days off to take their child to appointments (p. 305).
*Poverty S3, S18	S18: Poverty and its associated problems made seeking care more difficult...because of poverty, some parents may push aside their developmental concerns because of more pressing economic needs (p. 304).
Costs of evaluation/limited insurance coverage S4, S5, S17, S18	S4: ...*The insurance is the biggest thing. [It] will not pay for anything (p. 415).* S17: Cost of ASD evaluation (p. 6). S18: Although few parents directly said they lacked money to pay for diagnostic appointments (probably because most children in the study were publicly insured), several said the cost of appointments might affect other families (p. 304).
Transportation challenges S2, S17, S18	S18: ...Lack of money for transportation...made appointments harder to schedule (p. 305).

	Getting a diagnosis for many families meant...often having to rely on medical transportation or public transit to take them long distances (p. 305).
Legal barriers	
S3, S15, S17	S3: Changes and disruptions in caregiving and custodial arrangements created a barrier to following up on ASD screening and their primary healthcare providers' referrals to developmental evaluations for some caregivers, delaying their child's ASD diagnosis (p. 330). S15: ...Some participants expressed a fear of approaching service providers because of their immigration status (p. 765).

Note. All excerpts are direct quotations from primary studies.
Italicized text indicates participant quotations.
* Indicates factors associated with later age of diagnosis found in Daniels & Mandell (2014).

Table 3

Parent-reported Facilitators to Obtaining an ASD Identification

Facilitators	Excerpts
Knowledge	
*Parent knowledge of child development S7, S16	S7: *"When his sister was three (years old) . . . she didn't have the same symptoms or the same behavior patterns as he did. Like she spoke a lot, she was so social so I thought, okay maybe there is something going on. . . .*" (p. 259). S16: Parents consistently reported that their child failed to meet developmental milestones (p. 203).
Parent knowledge of the importance of identification S9, S16	S16: Parents often mentioned the practical benefits of getting a diagnosis, including getting ASD-specific services and funding, which was why they were determined to get the right diagnosis *("The diagnosis was really only a way for us to guarantee that we could get him the help that he needed, as in the funding from the county, state, whatever, as well as the special schooling that he needed.")* (p. 205).
*Parent knowledge of/familiarity with navigating the identification process S12, S16	S12: Overall, the most frequently mentioned facilitator for obtaining diagnoses was having the knowledge and resources for swift and effective navigation of services (p. 25).
Provider knowledge of ASD S12, S14	S14: Finally, an overwhelming majority of the participants indicated that they were happy with the information they received from professionals with specialized training in autism once they were able to meet with them (p. 88).
Proactive parent responses	
Parent persistence S3, S7, S8, S10, S15	S3: *I remember telling [pediatrician] that [child] is not saying any words. The pediatrician said, ''Well, some kids, it takes some time. Some kids, might be until two to speak.''...[T]here was a point where [child] just stopped [speaking]. The foods he liked, he wasn't eating anymore...I kept going to the pediatrician. ''Something's not right. Why is he not speaking?'' and [pediatrician] kept coming up with all these excuses...We gave it a few months, still nothing. I was like, ''I'm very, very concerned.'' I didn't know what was going on at all. But, all I knew was he's not talking and children are supposed to be meeting these milestones and he's not. We had to keep pushing* (p. 328).

	S7: *It took us three years to get him that IEP. They kept saying no he's fine* (p. 260).
Parents who sought their own information S15, S16	S16: ...Parents reported two main sources of information—the Internet or other media *("I read all available information and books that were recommended to me, and said, 'Okay, now everything [ASD] makes sense.'")* and people they knew (e.g. school professionals, friends or family members)...Parents also sought out specific information regarding evaluations and the diagnosis of ASD, and a few began to make appointments with medical or mental health professionals specialising in ASD (p. 203-204).
Proactive professional responses	
Professionals who voiced concerns/encouraged evaluation S12, S13, S15	S15: Families reported that school providers were often the first to prompt parents to seek an evaluation (p. 766).
*Professionals who made referrals S1, S2, S3, S12, S15	S3: These providers referred families to early intervention services for developmental evaluations when either the caregiver or provider was first concerned (p. 328).
Professionals who were attentive to parent concerns S1, S2, S3, S6, S12, S13	S3: All of the children whose caregivers reported their primary healthcare providers listened to their concerns were diagnosed with ASD by four years old or younger, and many before three years old (p. 328). S6: The doctor talked '*with feeling*' during the consultation. Their doctor's familiarity with their languages and culture provided a comfort zone for the parents (p. 804).
Social and community supports/resources	
Supportive friends, family, and outside network S2, S3, S12, S15, S16	S15: Participants shared the importance of having their family involved in the initial diagnostic process, including recognizing first signs and recommending an evaluation, as well as providing emotional and other logistical supports (p. 766). Caregivers noted that networking with other families, attending support groups and informal meetings with other caregivers, calling other caregivers, and sharing knowledge and experiences were helpful throughout the beginning of their child's diagnostic process (p. 767).

Availability of alternative diagnostic services provided by community organizations S12, S15	S12: *Because it took so long to get in to see Dr. M [developmental pediatrician], I went through [community organization] and I was able to get in to see one of their therapists and she was the one who diagnosed him* (p. 23).
ASD media exposure S8, S12	S12: *And it just so happened that at that time I think Toni Braxton was coming out and Jenny McCarthy was coming out and I am like oh my gosh, he does that. And, so, I just think that like, if I didn't watch that or see them on Good Morning America, you know, I wouldn't have known anything either* (p. 24).

Note. All excerpts are direct quotations from primary studies.
Italicized text indicates participant quotations.
* Indicates factors associated with earlier age of diagnosis found in Daniels & Mandell (2014).

Table 4

Participant Characteristics (N = 35)

Parent Characteristics		Child Characteristics	
Current Age	36.77 (5.54) [27.00 – 47.00]	Current Age	9.37 (4.77) [2.00 – 22.00]
Education		Sex	
High School/Less	9 (22.86%)	Female	5 (14.29%)
Associates/Bachelors	18 (51.43%)	Male	30 (85.71%)
Masters	9 (22.86%)	First Identification	
Income		Clinical Diagnosis	15 (42.86%)
$30,000 – $49,999	3 (8.57%)	Educational Eligibility	20 (57.14%)
$50,000 - $69,999	8 (22.86%)	Age Identification	4.13 (2.29) [1.33 – 13.00]
$70,000 - $89,999	7 (20.00%)	Prior Developmental Delay	15* (42.86%)
$90,000 – $150,000	12 (34.29%)	Intellectual Disability	8** (22.86%)
>$150,000	5 (14.29%)	Child's Insurance	
Location		Public	9 (25.71%)
Rural	5 (14.29%)	Private	16 (45.71%)
Suburban	19 (54.29%)	Both	10 (28.57%)
Urban	11 (31.43%)		

Note.

* = Two participants indicated being unsure about whether their child had a prior developmental delay

** = Seven participants indicated being unsure about whether their child had an intellectual disability.

Table 5
Hmong Parents' Endorsements of Causes of ASD

Causal Factors	Currently Believe	Used to Believe	Never Believed
Atypical brain development	62.86	14.29	22.86
Genetics	60.00	17.14	22.86
Chemical imbalance (child)	45.71	28.57	25.71
Problems during pregnancy	37.14	14.29	48.57
Mother's nutrition during pregnancy	28.57	8.57	62.86
Problems during birth	25.71	11.43	62.86
Mother's illness during pregnancy	25.71	14.29	60.00
Toxins	22.86	11.43	65.71
Accident or injury to child	14.29	8.57	77.14
Early childhood illness (child)	14.29	14.29	71.43
Alcohol, smoking, and/or drug use during pregnancy	14.29	11.43	74.29
Father's age at conception	11.43	17.14	71.43
Mother's age at conception	11.43	17.14	71.43
God's will	11.43	17.14	71.43
Vaccines	11.43	14.29	74.29
Child's diet	8.57	8.57	82.86
Early childhood trauma (child)	8.57	14.29	77.14
Tragedy from past life	8.57	5.71	85.71
Germ or virus	5.71	2.86	91.43
Child's name	2.86	0.00	97.14
Lost or stolen soul (child)	2.86	8.57	88.57
Karma or punishment	2.86	25.71	71.43
Allergies (child)	0.00	5.71	94.29
Bad parenting	0.00	11.43	88.57

Note. N = 35

Table 6
Parent-Reported Barriers to ASD Identification

Causal Factors	%
Autism is not talked about in the Hmong community	65.71
The process to get my child tested for autism was long	65.71
Autism is seen as a bad thing in the Hmong community	57.14
I had to wait a long time before my child could get an appointment to be tested for autism	54.29
I did not want to believe that my child has a disability	51.43
The process to get my child tested for autism was confusing and stressful	48.57
Family and friends told me not to worry	48.57
I did not know enough about autism	40.0
I did not know enough about child development	37.14
Doctors told me not to worry	37.14
Doctors did not know if my child's behaviors were because of autism or because of language	34.29
My child did not get screened for autism	31.43
I did not have time to take my child to his/her evaluation appointments because of my job	31.43
I had to meet with many doctors to get my child tested for autism	28.57
My child did not like the testing procedures for autism	22.86
My child has/had another condition	22.86
I had trouble getting to the evaluation appointments	20.00
Doctors did not communicate with me	20.00
It was hard to find help in the area that we lived	20.00
Doctors did not know enough about autism	17.14
My child did not show many signs of autism	17.14
Information on autism is mostly in English	17.14
Doctors did not listen to what I had to say	14.29

Doctors did not understand my culture	14.29
I was treated unfairly because of my race/ethnicity	11.43
I did not have money to pay for the evaluation appointments	11.43
Teachers did not know enough about autism	8.57
I did not trust the doctors	8.57
Teachers did not know if my child's behaviors were because of autism or because of language	8.57
I had trouble finding a babysitter	8.57
My child is a girl/female	5.71
Teachers did not communicate with me	5.71
Teachers told me not to worry	5.71
Teachers did not understand my culture	5.71
Teachers did not listen to what I had to say	2.86
I did not trust the teachers	2.86
I had trouble speaking and/or understanding English	2.86
There was no interpreter or the interpreter was not good	2.86
I wanted a doctor who could speak my language	2.86
I did not have insurance or my insurance did not cover the costs of the evaluation appointments	2.86
An autism screener found that my child was not at risk for autism	0.00
My child did not live with me	0.00

Note. N = 35.

Table 7
Parent-Reported Facilitators to ASD Identification

Facilitators	%
I kept pushing and trying	97.14
I could speak and understand English	94.29
I tried to find my own information	82.86
I knew about child development	80.00
I knew about autism	77.14
Teachers were knowledgeable about autism	74.29
Teachers listened to my concerns	74.29
My child showed many signs of autism	74.29
Doctors listened to my concerns	71.43
Doctors were knowledgeable about autism	65.71
Teachers encouraged me to get my child tested for autism	57.14
Doctors referred me to someone who could test my child for autism	57.14
I knew someone with autism	51.43
Family/friends were supportive	51.43
I knew what to do to get my child tested	48.57
I heard about autism on the news or social media	45.71
Teachers told me they were worried about my child	42.89
Teachers tested my child at school for autism	42.89
Doctors encouraged me to get my child tested for autism	37.14
Doctors told me they were worried about my child	28.57

Note. *N* = 35.

Table 8
Information Sources Endorsed by Hmong Parents

Information Sources	%
Internet search engines (Google, Yahoo, Wikipedia)	97.14
Doctor or other healthcare provider	91.43
Research articles	85.71
Other parents of autistic children	80.00
Teachers or other educators	74.29
Books	68.57
Individuals with autism/autistic people	62.86
Facebook	60.00
Friends	57.14
Online/in-person workshops/conferences	51.43
Blogs	48.57
Emails	45.71
Family members	45.71
State child find programs	40.00
YouTube	40.00
Newsletters	34.29
Podcasts	25.71
Instagram	22.86
TV	20.00
Pinterest	8.57
Radio	8.57
Reddit	2.86
Twitter	2.86
Tumblr	0

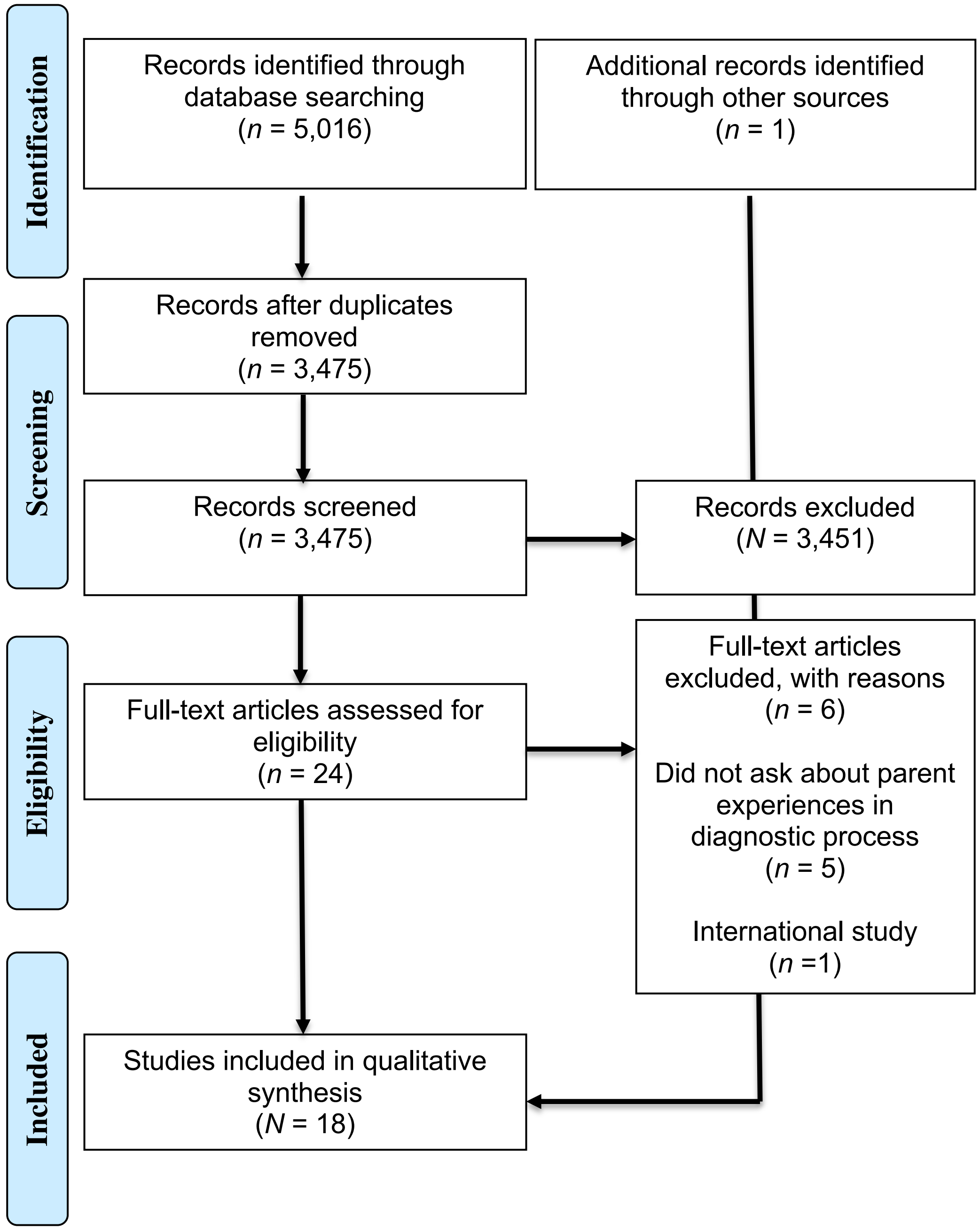
Note. $N = 35$.

Table 9
Encounters with and Usage of ASD Information Presented in Hmong Text and Audio

	Hmong Text	Hmong Audio
How often do Hmong parents encounter ASD information presented in Hmong text and audio?		
All the time	0.00	0.00
Most of the time	0.00	5.71
Some of the time	17.14	20.00
None of the time	82.86	74.29
How often do Hmong parents use ASD information presented in Hmong text and audio?		
All the time	14.29	20.00
Most of the time	2.86	8.57
Some of the time	22.89	14.29
None of the time	60.00	54.29

Note. N = 35.

Figure 1
PRISMA Flowchart



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