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Immigrant Mothers' Experiences in Accessing and Utilizing Education and Health care Services for Children with Intellectual and Developmental Disabilities: A Scoping Review

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A thesis submitted in partial fulfillment of the requirements for the degree of Master of Public Health
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Abstract

As the number of immigrants arriving in the US increases, it is necessary to understand the barriers they face in adapting to a new country to help ease their transition and improve their quality of life. One aspect of the immigrant experience that remains under-researched is the experiences immigrant mothers of children with intellectual and developmental disabilities (IDD) have in navigating the health care and education systems. Immigrant mothers are held to higher standards than non-immigrant mothers in raising their children and are usually expected to advocate for their children's education and health care. It is crucial that immigrant children with IDD have access to the necessary resources to thrive in and out of school and that their mothers feel supported in these efforts. A scoping review was conducted to gain insight into the experiences of immigrant mothers in obtaining these resources. A search across three databases yielded 716 studies, of which 19 were selected for review if they focused on the experiences of immigrant mothers, on children under 18 years old with IDD, and on either education or health care services. The studies were synthesized and categorized as either positive or negative experiences with the education or health care systems. The factors that impacted mothers' experiences varied. How school administrators, staff, and health care practitioners navigated the language barrier between them and the mothers played a significant role in how these women felt they were treated. The findings highlight some of the factors that help or limit the efforts of immigrant mothers in caring for their children with IDD in the US. More research needs to be done on this topic to facilitate the creation of policies that hold school administrators, staff, and health care practitioners accountable for providing adequate services for children with IDD in collaboration with their mothers.

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Introduction

The number of immigrants in the US continues to rise, with a record 47 million foreign-born individuals residing in the US in April 2022 (McHugh, 2022). It is predicted that immigrants and their descendants will make up 88% of the growth of the US population by 2065 (Xu et al., 2022). With this increase in immigrants comes a heightened awareness of the disparities immigrants face that prevent them from successfully adapting to life in the US. These barriers reflect the natural learning curve that comes with adjusting to the sociocultural norms of a new country and the limitations that US federal, public, and health care services have in providing resources to meet their needs. Studies examining the experiences of immigrants adjusting to life in the US have documented these obstacles and proposed solutions to ease their transition (Sloane-Seale, 2005). One aspect of the immigrant experience that has remained under researched but is crucial to their ability to live a satisfactory life is the experience of immigrant parents of children with intellectual and developmental disabilities (IDD).

Intellectual and developmental disabilities (IDD) is a bracket term that describes a child diagnosed with an intellectual and/or developmental disability that is likely to be present throughout their lives (Xu et al., 2022). Developmental disabilities describe a broad group of conditions, including intellectual disabilities, characterized by an impairment in physical, language, behavior, or learning abilities before the age of 22 years (Rubin & Crocker, 2022). Intellectual disabilities are characterized by severe adaptive behavior and intellectual functioning limitations before the age of 22 years (AAIDD, 2023). While there is extensive published research on the experiences of non-immigrant parents of children with disabilities, there is less on those of immigrant parents, particularly mothers (Neely-Barnes & Dia, 2008). Immigrant mothers often take the primary caretaker role of a child with IDD and face hardships in accessing

care for them (Kang et al., 2018). How her child is treated and perceived —whether positive or negative—is typically indicative of how she is treated and perceived (Lee et al., 2021).

Immigrant mothers also face three social burdens. The first burden results from being a mother. Mothers face higher scrutiny and are held to higher standards than fathers in raising their child (Khanlou, et al., 2017). They are judged by socially constructed notions of what it means to be a good mother, and any deviation from these notions result in social criticism or isolation. The second burden exists for women who are mothers of children with disabilities, because society stigmatizes the disabled, yet expects the mother to adequately provide for them (Akbar & Woods, 2019). Having a foreign-born status results in the third burden, because the challenges of accessing and using services for a child with IDD is amplified by being an immigrant—especially being a part of a racial or ethnic minority group. Because mothers are often the main caregiver and are held to high societal expectations of motherhood, they are the ones expected to advocate for their child, a concept known as the “Good Advocate Mother” (Khanlou, et al., 2017; Kibria & Becerra, 2020). A “Good Advocate Mother” is ideally supposed to manage her child’s education, ensure proper disability service delivery, and dispute services not in their child’s favor (Kibria & Becerra, 2020).

While some immigrant mothers can take on this role, others face difficulty in doing so, with language barriers being one of the main obstacles (Al-Hassan & Gardner, 2002). School administrators and special education teachers often fail to communicate with immigrant mothers—especially those who do not speak English—about the types of services available for their child (Khanlou, et al., 2017; Landa, 2021). They also fail to follow the rules outlined in the Education for All Handicapped Children Act (EACHA) passed by the US government in 1975 (Cho & Gannotti, 2005). This law requires schools to provide each disabled child with an

Individualized Education Program (IEP) and an IEP team. The IEP is a document that lists the child's learning needs, goals to fulfill them, ways to assess their progress, and the services the school will provide to achieve them (Kibria & Becerra, 2020). The IEP team is typically composed of the child's parents, school district representatives, teachers, and therapist. The EACHA also permits parents to approach the school with any concerns, such as perceived discriminatory practices, and for the school to help resolve them (Kibria & Becerra, 2020).

Some immigrant mothers have had an easier time than others when it comes to advocating for their child. Those who can speak English have had more success in communicating with their children's school administrators and health care providers (Al-Hassan & Gardner, 2002). For those who cannot speak English, the information and resources gleaned from immigrant support groups in their communities have given them the knowledge they need to help their children (Kibria & Becerra, 2020). Instead of letting their immigrant status or language barrier limit them, these mothers use their sense of personal responsibility for their child's wellbeing to educate themselves on their child's disability.

Immigrant children with special health care needs have a higher risk of having their health care needs unmet compared to non-immigrant children (Yu et al., 2004). Many immigrant mothers do not understand the complex US health care system and face difficulties finding providers for their child (McKay, 2019). Some barriers that exist for mothers in navigating the health care system include different cultural views on disabilities, language barriers, and distrust of medical providers (Khanlou, et al., 2017; McKay, 2019). Some mothers are highly influenced by cultural values from their country of origin, which may affect their perception of their children's health needs and determine how much they rely on help from health care professionals like pediatricians or therapists. One study comparing Asian and Muslim mothers of children with

IDD found that Asian mothers were more inclined to seek professional support for their children compared to Muslim mothers because they held professional advice to a higher standard than familial advice. Muslim mothers, guided by Islamic laws which stipulated family and community as the primary sources of support, relied on advice from their relatives rather than medical professionals (Neely-Barnes & Dia, 2008). Having limited to no English proficiency limits the understanding mothers have about their children's condition and actions that need to be taken to manage it. Some mothers have also expressed feelings of discrimination against them and their children by health care providers, leading to feelings of mistrust (Khanlou, et al., 2017).

Over 10 million children are children of immigrants, yet immigrant children with IDD make up a smaller portion of this population compared to non-immigrant children (McKay, 2019). Gaining insight of the experiences their mothers have in accessing and using services for them could help educate health care providers, school administrators, and staff on their needs. No other study has explored the literature on both the educational and health care related services available to immigrant mothers in the US. Most studies on the experiences of immigrant parents of children with IDD focus on both parents rather than the mother alone or are not US-based. Thus, this study has three main objectives:

1. To synthesize the literature about the positive and negative experiences of immigrant mothers of children with IDD in accessing and utilizing educational and health care services for their children in the US.
2. To explore the role of public schools and educational policies in improving or limiting successful integration of children with IDD.
3. To explore the role that health care services for children with IDD play in improving or limiting their quality of life.

Methods

Research design

Because this topic is under researched, a scoping review using the JBI framework was deemed the most appropriate research method. Scoping reviews thematically summarize findings on topics with limited data (Aromataris & Munn, 2020). This method also aims to identify gaps in the existing literature about a topic (Aromataris & Munn, 2020). The JBI approach to scoping reviews is the most influential framework used for this type of study. It involves six steps: 1) Identifying the research question, 2) Developing inclusion/exclusion criteria based on the research question, 3) Identifying specific data to pull from selected studies, 4) Searching for the studies, 5) Selecting and thematically analyzing the data, and 6) Extracting the evidence. The PRISMA-ScR checklist will be used to ensure the appropriate methodological guidelines for conducting scoping reviews are adhered to (Aromataris & Munn, 2020).

Search Strategy

A formal search in databases PubMed, CINAHL, and Ovid Embase was conducted after collaborating with a public health librarian to create a search strategy. The search strategy was the same for each database except for the field codes which differed depending on the database (Appendix). Additional studies were found by using articles cited in the reference lists of the selected studies.

Inclusion Criteria

Before the title and abstract review, all search results were filtered to between 2000-2022 to garner more recent data. Studies ultimately chosen for inclusion in this review had to be in English, focused on immigration to the US, and focused on children 0-17 years old with IDD. All study designs were included to maximize the number of results received.

Exclusion Criteria

Studies that did not have free full text, were published before 2000, were non-English, and were not based in the US were excluded.

Data Extraction and Analysis

The retrieved articles were reviewed independently by the student using Zotero, a software used to organize and manage bibliographic data. The review was completed in two screening stages. After an initial read through of the abstract and title, studies deemed ineligible were eliminated. For the full text review, the final selection of articles were chosen if: 1) they focused on the experiences of immigrant mothers, 2) focused on children under 18 years old with IDD, 3) focused on services provided by the education system, and/or 4) focused on health care related services. The articles that fit these guidelines were selected for a final, in-depth read-through, and synthesis of observed themes and gaps was completed.

Results

An initial search across all databases in January 2023 yielded 716 articles. After removing duplicates through Zotero, 702 articles remained. The author read through each abstract and title and eliminated articles based on the inclusion/exclusion criteria, leaving 34 articles. After a full text review of the 34 articles, 15 articles were selected. Out of the 34 articles, 16 were eliminated due to not distinguishing between mothers and fathers in their discussions of immigrant parent experiences, one article was eliminated due to not being peer-reviewed, and two were not US-based studies. A search through the references of the 15 articles led to four additional studies being added. **Figure 1** in the appendix summarizes the search and elimination process.

Article Characteristics

Out of the 19 articles, 13 focused on parental experiences but had perspectives from mothers which were used for the analysis. Seven articles focused on education-related experiences, three focused on health care experiences, and the other nine discussed experiences in both domains. In terms of study design, there were 13 qualitative studies, one scoping review, two formal reports, one integrative review, one systematic review, and one meta-synthesis. The following information was extracted from each study: author(s) last and first name(s), title, type of study, mothers' country of origin, year of publication, and summary of findings (**Table 1**).

Findings and key themes

The themes found during this review can be summarized into 1) positive experiences for mothers navigating the education system for their children, 2) negative experiences for mothers navigating the education system for their children, 3) positive experiences for mothers navigating the health care system for their children, and 4) negative experiences for mothers navigating the health care system for their children.

Positive Experiences: Education

The most common instances in which mothers had positive experiences navigating the education system for their children with IDD was when they were included in the process. Several studies included narratives in which mothers discussed their involvement in IEP meetings and other school-based programs for their children, such as workshops or disability training (Alvarado, 2004; Cho & Gannotti, 2005; Hwang et al., 2022; Jegatheesan et al., 2010; Lee & Park, 2016; Park & Turnbull, 2001; Zechella & Raval, 2015). Some learned how to help their children with schoolwork at home, teaching them how to use technology to simplify assignments (Cho & Gannotti, 2005; Zechella & Raval, 2015). Others proactively searched for

ways to help their children on the internet (Cho & Gannotti, 2005). One mother attended every IEP meeting and would only sign a form saying the IEP had been completed to her satisfaction when all her child's needs were met (Zechella & Raval, 2015). She visited her son's classroom, presumably to see his learning environment, and found the IEP generally responsive to her opinions and requests (Zechella & Raval, 2015). Another woman drove her autistic son to school to ensure he was safe and spoke as much English as she could when helping her son with schoolwork (Jegatheesan et al., 2010). This strategy suggests that she believed speaking the predominant country's language when doing homework with her child was beneficial to his academic progress. Mothers who enrolled their children in early intervention programs to help them manage their developmental disabilities felt comfortable advocating for their children if they disagreed with any advice given. One Spanish-speaking mother was told by her son's speech therapist to not teach her son—who had a speech delay—English words to avoid confusion while he learned to speak their native tongue. However, she continued to do so without any hesitancy because she strongly believed learning English early was best for him (Alvarado, 2004).

Social networks or support groups—with other immigrant parents from the same countries—were another way mothers gained information about accessing school-based disability services for their children (Lee & Park, 2016). One mother learned about the IEP process from a Korean-American support group for parents (Lee & Park, 2016). Support groups provided a means to share experiences with other immigrant mothers of children with IDD and exchange tips and advice in advocating for their children in the school system (Lee & Park, 2016). One mother found out about her legal right to access education services for her child

through a Korean-American mediator who also had a child with a developmental disability (Park & Turnbull, 2001).

Other positive experiences came from mothers' perception of the education system and pleasant interactions with school administrators and faculty. Mothers immigrated to the US from their respective countries because they believed the US had better educational resources for their children and saw US education as a blessing (Hwang et al., 2020; Lee et al., 2018). They were grateful when school administrators demonstrated cultural competency in treating their children, especially when working with the mother to establish clear goals for them to thrive academically (Cho & Gannotti, 2005). Teachers were another source of information. Some mothers would not have known about their children's disability or the IEP program without the teachers' keen observations. Upon noticing signs of a developmental delay, these teachers let the mother know their concerns and let her make the decision about whether to get her child tested or not and when (Cho & Gannotti, 2005; Luelmo et al., 2020; Park & Turnbull, 2001). Mothers appreciated it when their children's teachers were friendly to them. One mother noted how happy she was to see that her daughter, who had multiple severe developmental disabilities, could still participate in school programs because her teacher made accommodations (Park & Turnbull, 2001). Her daughter won a pizza coupon for her attempt at an in-class activity. Others shared positive experiences during IEP meetings. Whereas mothers with negative experiences shared the intimidation that came with all the professionals being present, others thought of this environment as being surrounded by key players who cared for their children (Cho & Gannotti, 2005). Because English was still a barrier to them, the professionals who were patient and tried to communicate with them made these mothers feel respected.

Negative Experiences: Education

Findings from this scoping review suggest that most of the negative experiences immigrant mothers of children with IDD had in dealing with the education system was accessing IEP resources for their children. The language barrier only magnified the complications these women faced (McKay, 2019). Several mothers were not informed of their children's IEP rights by the school and only found out through someone in their community or on their own after some time (Hwang et al., 2020; Lee et al., 2018; Lo, 2018; Luelmo et al., 2020; Park & Turnbull, 2001; Xu et al., 2022). They did not know their children had access to individualized education as required by the Disabilities Act and sometimes were pushed to sign documents falsely saying they had received adequate IEP services when they had not (Hwang et al., 2020). Immigrant mothers who did find out about IEP services were still confused and not given clear directions on how to utilize such services (Alvarado, 2004; Lee et al., 2018; Lo, 2018).

To access IEP services, the mother had to attend meetings initiated by the school, which included school administrators, the child's therapist, and their assigned special education specialist (Lee et al., 2018). These meetings were the source of most of the negative experiences associated with the education system that mothers encountered. Some mothers experienced blatant disrespect while attending these meetings. In some of these meetings, at least one professional would arrive late or leave early, which mothers found disrespectful since they usually took unpaid time off work to attend these meetings (Cho & Gannotti, 2005; Salas, 2004). Lo (2018) found a few instances of poor behavior on the part of the IEP team. One mother interviewed, said that when she expressed concerns about the safety of her son (diagnosed with Hunter syndrome) in school without proper supervision, the professionals called her overprotective and said she asked too much of the school. Another was told that her methods of

evaluating her child's progress were not as sophisticated as that of the school's. Another mother with an autistic child was openly criticized by one professional in front of the others about her lack of discipline for her son, who was not progressing educationally. These are just some examples of the mistreatment immigrant mothers faced during IEP team meetings and being unable to speak English prevented some women from speaking up more. One mother got so used to professionals using the IEP meetings to berate her for her child's behavior that she dreaded going to them (Salas, 2004).

Another method of disrespect was the lack of willingness to listen to or acknowledge the mothers' perspectives in matters that concerned their own children. Some women believed the professionals intentionally marginalized them and discounted their concerns or comments about their children's educational outcomes. Whenever they suggested a goal for their children that was different from what the IEP team suggested, their requests were usually denied and it would take multiple tries until the requests were fulfilled (Cho & Gannotti, 2005).

The logistics of IEP meetings were also confusing for immigrant mothers. The timing was often inconvenient for those who had to take unpaid time from work, which was why they felt disrespected when professionals would arrive late or leave early. Some mothers found the entire environment intimidating, with some meetings having up to 10 professionals in the room with their sole attention on the mother (Lo, 2018; Salas, 2004). Mothers interviewed for Lo's (2018) study were unclear about what these meetings were for or how professionals arrived at their judgments. One woman was told her daughter with cerebral palsy would no longer receive school-based occupational therapy. Instead, the therapist would consult her daughter's teacher on her progress for five minutes once a week, which she felt was unhelpful. A woman interviewed for Alvarado's (2004) study said she was notified about the ending of her three-year-old

daughter's early intervention program received no guidance on the next steps to take to access more care for her. Professionals also tended to use complex words associated with special education or associated with their children's condition that even translations could not clarify (Lee et al., 2018; Lo, 2018; Salas, 2004). Mothers expressed annoyance at being given written reports that they were expected to read and understand (Lee, 2018; Park & Turnbull, 2001). At times the IEP team would talk about all this information without ensuring the mothers understood it, leaving them unaware of the progress of their children.

The use of interpreters ironically added to these women's negative experiences. At times they did not know how to translate the jargon used by the professionals (Lo, 2018). During the IEP meetings, professionals would say a lot of information before allowing the interpreter to speak, and the interpreter would summarize the statements and miss key points (Lo, 2018; Park & Turnbull, 2001). Some IEP teams did not even offer interpreters (Lo, 2018; Cho & Gannotti, 2005). The numerous struggles mothers had in their interactions with school administrators made them struggle with how to act around them. They were not sure if acting assertive or compliant was the better option and their approaches depended on a few factors. Some of the authors who focused on mothers from South Korea noted that Korean culture emphasizes respect for teachers and to avoid questioning them, thus some Korean immigrant mothers would not question teachers (Hwang et al., 2020; Park & Turnbull, 2001). Other Korean immigrant mothers did not care how they acted because they realized that if they did not advocate for their children, no one would. To them, being in the US meant they no longer had to practice obedience because obedience would not always get their children the help they needed (Xu et al., 2018; Park & Turnbull, 2001). Other mothers also struggled with this conflict. Some undocumented mothers from Mexico feared deportation as a result of challenging teachers so they stayed quiet (Luelmo

et al., 2020). Some feared speaking out would make the school administration and faculty treat their children poorly (Lo, 2018).

Another source of conflict came when mothers rejected advice from professionals. One woman who was Muslim believed Allah chose her to parent an autistic son because she would protect the child rather than neglect or harm him (Jegatheesan et al., 2010). This belief resulted in her rejecting teachers' and professionals' focus on her child's limitations as she saw them as Allah's will. While this rejection could be considered positive because she chose not to focus on the negative aspects of her child's limitations, some of the professional advice she did not follow could have benefitted her child, although the study did not explore that possibility. One final source of negativity for these mothers was found in a study that explored the experiences of immigrant mothers of a disabled child during the Covid-19 pandemic (Dababnah et al., 2021). Because her child was home, she worried about their ability to have social interactions in an educational setting due to the limitations brought upon by quarantine. While this study did not explore those concerns more in-depth, it adds another lens through which to think about the added challenges immigrant mothers face.

Positive Experiences: Health Care

Some immigrant mothers viewed the US health care system highly and believed their children would receive better quality health care in the US than in their home countries (Lee et al., 2021). One mother's child was diagnosed with a rare developmental disability, of which only two other children in the world were diagnosed. She did not think her child would have been diagnosed if they had stayed in their home country, South Korea. Along with positive perceptions of the US health care system, some immigrant mothers had friendly interactions with providers. These pleasant exchanges usually occurred when they felt heard and respected by the

providers and felt that the providers cared for their children. Some expressed an appreciation for therapists who would let them watch their children's therapy sessions or who would teach them parenting skills (Hwang et al., 2020; Park & Turnbull, 2001; Xu et al., 2022). Some therapists provided emotional support and shared hope about their children's future (Xu et al., 2022). Over half of the 20 mothers interviewed for Cho & Gannotti's (2005) qualitative study reported that the health care professionals who helped them were considerate. Women in this study appreciated early intervention programs and trusted the advice of the professionals who diagnosed their children. Some mothers appreciated the special attention they and their children received from providers, especially when they would take families without insurance (Suarez-Balcazar et al., 2021). All these studies specifically examined women with limited English proficiency; however, language barrier was not a major obstacle for parent-provider communication because providers either spoke slowly, avoided difficult medical jargon, or used an adequate translator (Cho & Gannotti, 2005; Hwang et al., 2020; Park & Turnbull, 2001; Xu et al., 2022).

Mothers with more positive experiences navigating the health care system tended to participate in their children's therapy sessions. By actively engaging and learning from the therapists, they could better care for their children and better understand their disabilities (Hwang et al., 2022; Lee et al., 2021). Through participating in these therapy sessions, one mother acknowledged the benefit of learning how to manage her child's IDD rather than trying to cure it (Kim & Dababnah, 2019). Some mothers did believe their child's disability could be cured and while that could be a negative perception, Park & Turnbull (2001), suggest the benefit is that it encouraged them to be more involved with their children's health care and follow professional recommendations.

Some mothers had positive experiences that did not involve interactions with providers. Having a child with a disability meant they were eligible for social benefits like Medicaid, making them less worried about medical care costs (Park & Turnbull, 2001). Others learned about health services available to their children through community members. In one study documenting the experiences of undocumented mothers, one received help from community-based organizations aimed at helping Spanish-speaking parents. Another undocumented woman was encouraged to put her child in an early intervention services program (Zechella & Raval, 2015). She assumed her child would not be accepted due to their status, but with the support of her social worker, her child was accepted.

Negative Experiences: Health Care

Most of the negative experiences immigrant mothers of children with IDD had in navigating the health care system came from poor interactions with providers. Some women felt disrespected by pediatricians. One noted that she repeatedly told her son's doctor that he was not speaking at an age when he should have been, but the doctor said that he was lazy or that it was normal behavior (Luelmo et al., 2020). The doctor, whom the authors acknowledged was White, did not request any testing for IDD. Because she was undocumented, she feared that continuing to press the doctor would get her deported. Many women believed that health care professionals focused more on the negative aspects of their children's condition than the positive and would make inappropriate comments about their children. These mothers also felt like the professionals did not care about their feelings and treated their children's care like a business transaction (Cho & Gannotti, 2005). Case managers were often hired to help immigrant parents connect with disability services, but many were difficult to get in touch with and were not always helpful with providing information about the services available for their children (Cho & Gannotti, 2005).

Along with having difficulty communicating with health care professionals, some mothers were reluctant to accept their advice due to mistrust. One study examining how South Asian Muslims' religious beliefs impact their perception of their disabled children's health suggested that mothers with strong beliefs may disagree with a provider's recommendations on how to treat their children. One woman, guided by her belief that her son was divinely chosen to have autism, took care of her son as she saw fit and rejected some of the suggestions made by professionals. She believed that professionals paid the most attention to her child's deficits rather than examining the child holistically (Jegatheesan et al., 2010). Another woman interviewed for Alvarado's study (2004) was advised to keep hand splints on her daughter, who has microcephaly, for several hours each day. However, she noticed that her daughter would sweat a lot with the splints on, which created an odor. To avoid the smell and ensure her daughter was comfortable, she continued to remove the splints at a certain point each day even if it went against the occupational therapists' advice.

The language barrier limited some mothers' understanding of what developmental disabilities were, and thus the terminology and jargon associated with IDD confused them (Lee et al., 2021). A lack of understanding of the health care system, how to find a provider for their child, how to afford that care, and how to maintain it were other sources of confusion and trouble for immigrant mothers. One mother described her struggle to navigate all the paperwork, appointments, and legalities of accessing health care services for her disabled child (Luelmo et al., 2020). She noted that not speaking English made accessing these services more complicated. Another study on Russian Jewish immigrant mothers showed that limited English proficiency hindered their understanding of the jargon health care professionals used (Alsharaydeh et al., 2019). Kummer et al. (2007), assessed immigrant mothers' perceptions of their children's

developmental delays. Findings showed that while mothers were aware that their children had some symptoms of a developmental delay (such as speech or language deficiencies), their perception of the cause of those delays varied. In addition to not understanding disabilities and the health care system, some participants had misconceptions about their children's conditions. Some believed the disability could be cured. One woman enrolled her son in a week-long intervention program hoping his developmental disability would be cured. She was disappointed when her son did not quickly progress, leading her to search for a physical therapist and neurologist to help (Park & Turnbull, 2001). Another expressed interest in brain surgery for her child, thinking it would cure them but was advised against it by medical professionals. Some women viewed IDD negatively. One mother refused to look at a booklet describing her child's disability because she feared learning about it and considered giving her child away for adoption at one point (Lee et al., 2021).

Another barrier mothers faced was the sudden discontinuation of health care services brought upon by the COVID-19 pandemic. A study done by Dababnah (2021) found that many of the services normally afforded to their children, such as social skills training, physical therapy, and speech-therapy, were discontinued with no alternative options available. Mothers of children who were provided services through telehealth were mainly dissatisfied with the quality compared to face-to-face therapy. One final barrier to accessing adequate health care was finances. Whether mothers were documented or undocumented, they faced financial crises because of the medical expense accrued once they sought care for their child (Alsharaydeh et al., 2019). Undocumented women with no insurance often delayed getting their child diagnosed or treated until they received help from community members (Luelmo et al., 2020).

Discussion

The purpose of this scoping review was to explore the positive and negative experiences immigrant mothers have in navigating the education and health care systems in the US. A scoping review was the best research method to synthesize the literature on this under-studied topic. Nineteen articles were selected for final review and yielded narratives split into positive and negative experiences. While their experiences varied, the language barrier mothers faced and how they were treated because of it influenced their perceptions. While the education system is a broad term covering many facets, the experiences documented in this review centered on IEP meetings. The meetings were a way to hold the school and parents accountable and ensure they were working together for the child's sake. There were times when mothers felt respected, heard, and validated by IEP team members and moments they did not, which elicited negative emotions. The experiences documented in this review of mothers navigating the health care system mainly surrounded their interactions with health care professionals. When therapists or other health care professionals advised moms on the best ways to care for their children, involved them in their sessions, and provided emotional support—all despite the language barrier—they had the most positive experiences. Negative interactions tended to elicit feelings of invalidation, confusion, and hopelessness among the mothers.

Several points could be made from the obstacle that the language barrier presented. First, many current systems in place to help mothers with children with disabilities rely on the mothers' understanding of English. By not understanding English, these immigrant mothers were at a disadvantage at every step. Second, immigrant mothers frequently had to rely on community members for help rather than the professionals assigned to help them. Third, some of the resources given to mothers—like case managers or translators—were not always equipped with

the skills and professionalism needed to help them. This study examined immigrant mothers' experiences through mainly qualitative studies, which appear to be the design that allows for the most insightful narratives. These experiences support the research done in countries like the UK and Canada on the same topic but add the perspective of immigrant mothers in North America dealing with a different education and health care system (Akbar et al., 2019; Khanlou et al., 2014; Khanlou, et al., 2017). The findings, while informative, suggest that there is still much more research that needs to be done on this topic in the US and efforts made to ensure immigrant parents, particularly mothers, are treated fairly in their interaction with education and health care professionals. One method to facilitate these efforts is to make health care professionals practice the National Culturally and Linguistically Appropriate Services standards (CLAS). These standards, created by the Department of Health and Human Services, are intended to improve the quality of health care services that those in marginalized communities experience. Some of the guidelines include offering free language assistance to patients, providing, easy-to-understand materials in different language, and maintaining a diverse, culturally competent workforce (National CLAS Standards, n.d.). The Department of Education could create a similar set of guidelines for school administration and faculty to adhere to as well.

Limitations

This scoping review had a few limitations. First, only one reviewer screened and extracted the data for this study, which increases the risk of bias and misclassification. Second, only three databases were used, and with a topic as under-researched as this one, more databases may have garnered more articles to select. Third, out of 19 articles, ten focused on parents or mothers of Asian descent, and four focused on mothers from Mexico, meaning only five had perspectives from other racial or ethnic groups. Finally, only two studies focused on the

experiences of undocumented immigrants, yet they offered a unique perspective on the topic that could not be fully captured.

Conclusion

The results from this scoping review show the unique challenges experienced by immigrant mothers in advocating for children with IDD. Unlike non-immigrant mothers, the language barrier often prevents them from truly engaging with the resources set by the education and health care systems to aid children with IDD. Notably, this review underscores that it is not only up to the mother to advocate; members of the IEP team, social service groups, and health care providers must practice more cultural competency in their interactions with these women. Policies, such as the nationwide implementation of CLAS, should be created to legally hold school and health care administrators accountable for how they advertise and implement disability rights so that mothers are informed and feel a part of the process. The positive experiences mothers shared suggest that language barriers can be overcome if both parties work towards that goal and focus on helping the child thrive.

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Appendix

Pubmed Search

“((mother* [tw] OR caregiver* [tw] OR parent* [tw] OR famil* [tw]) AND (immigrant* [tw])) AND ("disabled child*" [tw] OR "handicapped child*" [tw] OR "developmental disabilit*" [tw] OR "intellectual disabilit*" [tw] OR "disabilit*" [tw] OR "special need*" [tw] OR "special education" [tw] OR "child development" [tw])”

CINHAL Search

“AB (mother* OR caregiver* OR parent* OR famil*) AND AB immigrant* AND AB ("disabled child*" OR "handicapped child*" OR "developmental disabilit*" OR "intellectual disabilit*" OR "disabilit*" OR "special need*" OR "special education" OR "child development")”

Ovid Embase Search

“((mother* or caregiver* or parent* or famil*) and immigrant* and (“disabled child*” or “handicapped child*” or “developmental disabilit*” or “intellectual disabilit*” or “special need*” or “special education” or “child development*”).tw.”

Figure 1: PRISMA Flowchart of Study Selection

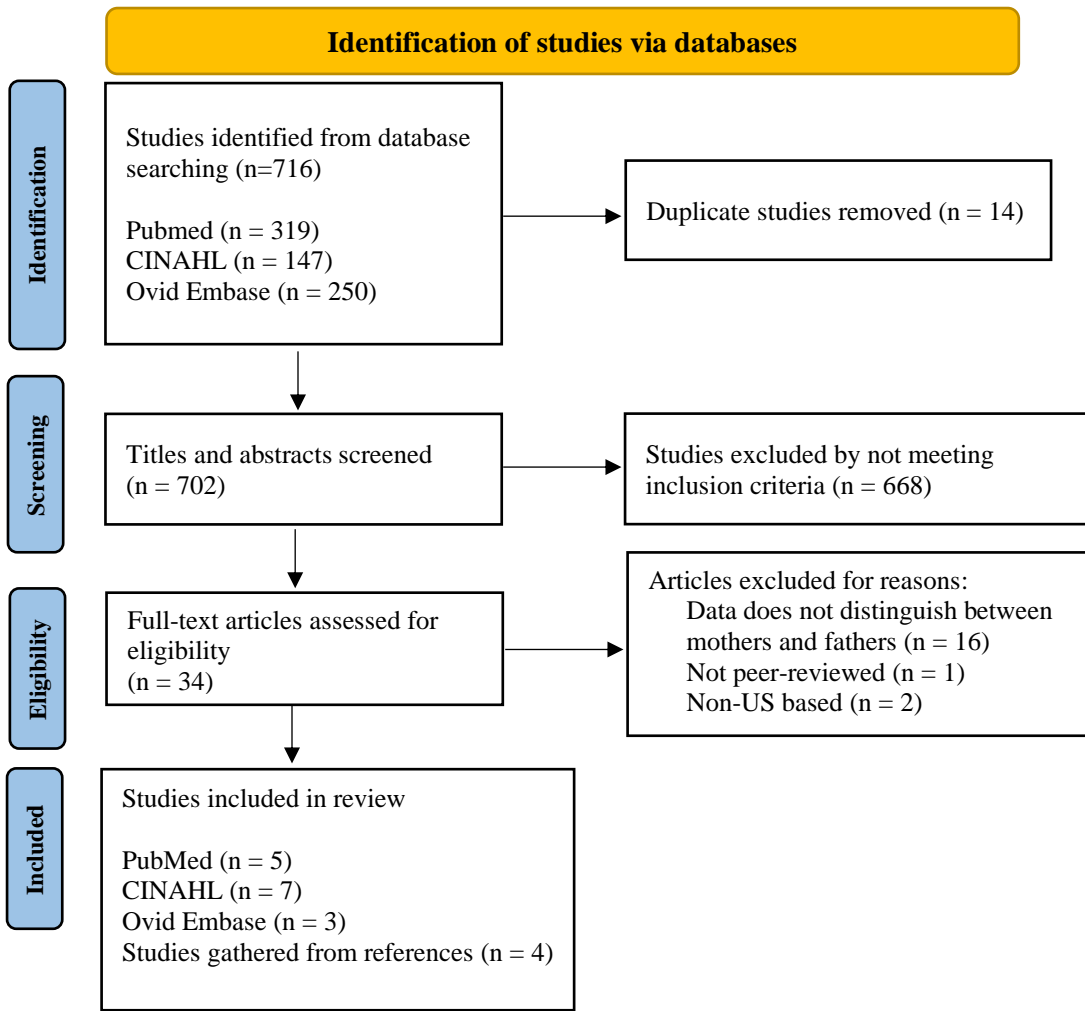


Table 1: Study Characteristics and Findings

Author(s), Year	Title	Design	Population	Findings
Alsharaydeh et al., 2019	Challenges, Coping, and Resilience among Immigrant Parents Caring for a Child with a Disability: An Integrative Review	Integrative Review	Russian, Indian, Mexican, Somali Bantu, South Asian, Taiwanese, South Korean, Haitian, Pakistani, and unspecified Asian parents	Mothers had a difficult time understanding the jargon health care professionals spoke in. Some mothers faced financial crises due to medical expenses accrued and those that were undocumented had no insurance to support them which caused difficulties in accessing care for their children.
Alvarado, 2004	Mucho Camino: The Experiences of Two Undocumented Mexican Mothers Participating in Their Child's Early Intervention Program	Qualitative	Undocumented Mexican mothers	Fear of deportation and language barriers were the two main obstacles these women faced in accessing resources for their children. Each woman had a close enough relationship with their child that they did not always take the providers word and sometimes used their own judgement in determining proper actions to take for their child.
Cho & Gannotti, 2005	Korean-American Mothers' Perception of Professional Support in Early Intervention and Special Education Programs	Qualitative	Korean parents	Language was a major barrier for mothers attempting to communicate with providers, however their experiences were both positive and negative. Mothers were satisfied when school administrators were kind to them and their child. Case managers and poor translators were the main sources of discontent for mothers attempting to access school-based resources for their child.

Dababnah et al., 2021	Brief Report: Impact of the Covid-19 Pandemic on Asian American Families with Children with Developmental Disabilities	Report	Asian parents	Covid-19 brought a few concerns for mothers including the temporary ending of in-person therapy and them having to take over as therapist and educator. Some mothers feared their children would not progress educationally.
Hwang et al., 2020	Asian Immigrant Parents' Role Enactment While Accessing and Using Services for Their Child With Developmental Disabilities in the United States: A Meta-Synthesis Study	Meta-synthesis on qualitative Studies	Asian parents	Mothers had mixed views about their roles as caregivers of children with disabilities. Korean cultural values on respecting professionals resulted in some mothers believing they should not argue with their child's teachers or health care providers. Others realized they had to be more assertive to get their desired needs met.
Jegatheesan, 2010	Autism From a Religious Perspective: A Study of Parental Beliefs in South Asian Muslim Immigrant Families	Qualitative	South Asian Muslim parents	This study focused on the influence of religious values on the ways parents, particularly mothers, perceived their children's disabilities and how their perceptions affected their interactions with professionals. One mother believed Allah chose her to care for her autistic child and thus she viewed her child's behaviors in a positive light. She did not pay as much attention to the negatives as much as the health care and education professionals did.
Kim and Dababnah, 2019	Appreciation of the 'Subtle Changes': Perspectives of Korean American Parents Raising	Qualitative	Korean parents	Parents' understanding of their child's disability varied. One mother acknowledged that therapy is less of a cure and more of a way to manage the condition. Other mothers believed their children could be cured and

	Children with Developmental Disabilities			used various treatment regimens to cure them.
Kummer et al., 2007	Mexican Immigrant Mothers' Perceptions of Their Children's Communication Disabilities, Emergent Literacy Development, and Speech-Language Therapy Program	Qualitative	Mexican mothers	Mothers had a limited understanding of their children's disability or of the importance of receiving therapy. Nonetheless, they noticed progress in their children's development through therapy.
Lee & Park, 2016	Becoming a Parent of a Child with Special Needs: Perspectives from Korean Mothers Living in the United States	Qualitative	Korean mothers	Mothers discussed the successes and complications they faced when working with health care and school-based professionals to care for their children. The joys came when there was collaboration between the two parties. Language barriers still made communication complicated and school administrators did not willingly publish information about IEPs, so mothers typically found out about them on their own. Some mothers were hesitant to speak out at first during IEP meetings but did not regret it once they did.
Lee et al., 2018	Advocacy for Immigrant Parents of Children with Disabilities.	Report	Parents from various countries but predominantly Korean and Hispanic parents/mothers	Many of the immigrant mothers interviewed did not speak English which prevented them from having fulfilling meetings with the IEP team. School administrators should teach cultural competency among employees to work through language barriers.

Lee et al., 2021	Perceived Experiences of Korean Immigrant Mothers Raising Children with Disabilities in the United States	Qualitative	Korean mothers	Mothers had generally positive experiences with the health care system and education system. Some mothers got involved in their children's lives through helping them make friends in school, sitting in on therapy sessions, and advocating for their child in school. Other mothers described the initial shock of finding out about the diagnosis along with confusion since they did not know what conditions, like down syndrome, were.
Lo, 2008	Chinese Families' Level of Participation and Experiences in IEP Meetings	Qualitative	Chinese parents	Three main barriers prevented the mothers interviewed from fully engaging in IEP meetings: 1) Language barriers along with inadequate interpreters, 2) Their input not being welcomed or accepted by professionals, and 3) Professionals disrespecting them during the meetings.
Luelmo et al., 2022	Undocumented Mexican Mothers of Children with Autism: Navigating the Health Care and Educational Service Systems	Qualitative	Undocumented Mexican mothers	Most of the mothers in this study did not know a lot about autism. They only knew their children had autism because their children's teachers told them. These mothers were hesitant to get their children tested, and some delayed evaluation for years due to the fear of being deported. Mothers were also hesitant about speaking up against the teachers or health care providers for fear of getting deported.
McKay, 2019	Immigrant Children with Special Health Care Needs: A Review	Systematic Review	Parents from various countries	Immigrant mothers faced immense difficulties in raising their children with IDD, particularly in communicating with health care providers due to the language barrier.

Park & Turnbull, 2001	Cross-Cultural Competency and Special Education: Perceptions and Experiences of Korean Parents of Children with Special Needs	Qualitative	Korean parents	<p>Most mothers had positive experiences in collaborating with their children's teachers for their care and behavior monitoring. The negative experiences resulted from the language barrier. Mothers wished professionals stopped to make sure they understood what was being said about their children. Most mothers found out about IEP from sources other than the school.</p> <p>When mothers received benefits like Medicaid or SSI, they felt more secure in being able to get proper medical care or assistive technology for their children with IDD.</p>
Salas, 2004	Individualized Educational Plan (IEP) Meetings and Mexican American Parents: Let's Talk About It	Qualitative	Mexican parents	The mothers interviewed had negative experiences. They were disrespected by IEP team members, told to be grateful for the services they were receiving, and found little support in their efforts to advocate for their children. These mothers found the IEP meetings intimidating or unproductive because they could not contribute to them due to the language barrier.
Suarez-Balcazar et al., 2021	Community-Engaged Asset Mapping with Latinx Immigrant Families of Youth with Disabilities	Qualitative	Parents from various Spanish-speaking countries	Mothers appreciated it when their children's health care providers paid close attention to the child and offered affordable prices for their services.
Xu et al., 2022	Barriers to Service Access for Immigrant Families of Children with Developmental Disabilities: A Scoping Review	Scoping Review	Parents from various countries	Immigrant mothers face many obstacles in their attempts to advocate for their children with disabilities due to the language barrier. As a result, some of the mothers studied felt powerless in accessing the proper resources and treatment for their children.

Zechella & Raval, 2015	Parenting Children with Intellectual and Developmental Disabilities in Asian Indian Families in the United States.	Qualitative Study	Asian Indian parents	Mothers in this study had positive experiences with navigating the health care and education systems. Some would serve as advocates, teachers, and caretakers for their child whether they were receiving professional help or not.
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