

Intellectual and Developmental Disabilities

Barriers to Services for Immigrant Families of Children with IDD: A Scoping Review

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Introduction

In the US, immigration has become a key topic for political and public debate. Immigrants account for 13.7% of the US population (US Census Bureau, 2018), and it is predicted that immigrants and their descendants will account for 88% of the US population growth through 2065 (Pew Research Center, 2015). According to a recent report, one in 4 children has at least one immigrant parent (Urban Institute, 2019). Many children of immigrant families live in low-income households, have parents with lower levels of education, and use fewer public benefits (Hernandez & Napierala, 2012; Greenberg et al., 2019).

Intellectual and developmental disabilities, or IDD, are a bracket term used to describe situations when a diagnosis of intellectual disability (ID) and/or developmental disabilities (DD) are present (National Institutes of Child Health and Human Development [NICHD], n.d.). Intellectual disability is characterized by co-occurring intellectual and adaptive functioning deficits that occur during the developmental period (American Psychiatric Association [APA], 2013), while DD is defined as a severe chronic disability of an individual that is attributable to a mental and/or physical impairment, is manifested before age 22, and is likely to continue indefinitely (Developmental Disabilities Assistance and Bill of Rights Act of 2000). A recent national study showed that the prevalence of IDD increased significantly among children and adolescents during the past decade (Zablotsky et al., 2019). While that number is likely to be increasing, we do not have an accurate estimate of the prevalence of IDD among immigrant children; neither do we know much about their experiences with services. Emerging evidence shows that racial and ethnic minority families of children with IDD experience disparities when compared to their White counterparts (Zuckerman et al., 2013; West et al., 2016; Bishop-

Fitzpatrick & Kind, 2017). However, immigrant families' experiences may be different from racial and ethnic minority families because immigration is a unique determinant of health (Castañeda et al., 2015). We need to better understand what disparities are faced by immigrant families of children with IDD to inform future policy and practice.

Disparities Faced by Immigrant Families of Children with IDD

Children with IDD require more healthcare and specialty services than children with other special healthcare needs (Boulet et al., 2009; Croen, et al., 2006; Krahn et al., 2006). Early intervention and services have been shown to positively impact both child and family outcomes, which lead to long-term savings for the families and the public welfare system (Koegel et al., 2013; Woodman et al., 2018). However, immigrants in general often face more challenges when accessing services given the complexities of acculturation, language barrier, and the lack of culturally appropriate services (Luque et al., 2018; Kalich et al., 2016; Mendoza, 2009). Existing literature has documented that immigrant families of children with disabilities are underserved in the current healthcare system (Singh et al., 2013; Kan et al., 2016). Persistent disparities prevent them from accessing quality healthcare, appropriate treatment, interventions, and services (Magaña et al., 2013; Magaña et al., 2015; Bilaver & Havlicek, 2019). In a study of children with special healthcare needs, Kan et al. (2016) documented the lack of care coordination and access to medical homes for children with foreign-born parents compared to those with US-born parents. Another study found that, compared to their counterparts with US-born parents, immigrant children with special healthcare needs have less access to, and utilization of care, and poorer perceived health (Javier et al., 2010).

Systemic factors may contribute to disparities. A national study on how immigration policy affected the rate of autism spectrum disorders (ASD) diagnosis found that the rates of

ASD diagnosis were similar between White and Latino children in some years, but were lower for Latino children in other years when immigration policy was tightened, or anti-immigrant sentiments rose (Fountain & Bearman, 2010). Zuckerman et al. (2013) found that primary care pediatricians had more difficulty identifying risks of ASD among Latino children from Spanish-speaking families than White children. Other studies exploring the mechanisms of disparities have documented the lack of culturally and linguistically appropriate care at both provider and healthcare system levels (McKay, 2019).

Barriers to diagnosis and treatment services often lead to adverse outcomes for both children with IDD and their family caregivers (Sritharan & Koola, 2019). There is a lack of systematic synthesis of existing literature on the disparities faced by these multi-dimensionally disadvantaged families. A close examination of disparities faced by immigrant families can help inform intervention design and clinical practices.

Three-Phase Health Disparity Research Framework

Health disparities are defined as "differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States" (US Department of Health and Human Services, 2002). Health disparities exist across different age groups in every aspect of health, including the utilization and quality of care, access to care, and health outcomes (Carter-Pokras & Baquet, 2002). In the past two decades, nationwide health initiatives such as Healthy People have prioritized reducing and eliminating health disparities for disadvantaged groups (Healthy People, 2019).

Meanwhile, health disparity research has also emerged as a critical aspect of public health and other interdisciplinary research agenda. To advance health disparity research, Kilbourne et al. (2006) developed a framework that classifies three phases of disparity research. Each phase

progresses and informs the next one: *Phase One Detecting Disparities* defines the problem and populations facing disparities, and measures disparities with consideration of other confounding social-environmental factors; *Phase Two Understanding Disparities* explores the determinants of disparities at the individual, provider, and healthcare system levels; *Phase Three Reducing Disparities* incorporates intervention, implementation and translation into routine care and policy change. Kilbourne et al.'s (2006) framework provides critical guidance in the direction of future disparity research, particularly populations that are disadvantaged in multiple dimensions such as children with IDD from immigrant families.

Current Study

This study sought to conduct a scoping review on existing research evidence from peer-reviewed journals and doctoral dissertations published between 2000 and 2020 on barriers and access to services among immigrant families of children with IDD in the US. Specifically, we aim to 1) present an overview of barriers faced by immigrant families of children with IDD when accessing services and care; 2) examine current research evidence on healthcare disparities among these families using Kilbourne et al.'s (2006) disparity framework; and 3) discuss implications for future research to strengthen the evidence in this field.

Methods

Scoping Review Protocol

We adopted Arksey and O'Malley's (2005) five-stages methodological framework. We first defined the research question, and then worked with a librarian to finalize a list of search terms and perform the searches. Third, we applied inclusion criteria to identify eligible studies. An ancestral search using the reference lists of the included articles and key researchers in the field was also performed to avoid leaving out potentially eligible studies. Fourth, we designed a

coding spreadsheet to document relevant themes to capture data from the included studies.

Lastly, the first and second authors independently read the full texts of the included articles, extracted relevant data using the coding sheet, and reported data.

Inclusion and Exclusion Criteria

Four inclusion criteria were applied to identify eligible studies. First, we included online peer-reviewed articles and published doctoral dissertations that focused on barriers and access to a wide range of services used by immigrant families of children (0-17 years old) with IDD in the US. We did not include studies that focused on transition since another recent scoping review has specifically covered culturally appropriate transition practices (Wilt & Morningstar, 2018). To emphasize immigrant families' experiences, we did not include studies that focused on provider's perspective. Additionally, therapeutic services such as occupational and physical therapies can be provided from both the healthcare system and the special education system. As we review the literature, health services such as diagnostic and therapeutic service disparities were identified across both systems. Second, studies were limited to those published between January 2000 to February 2020. We have witnessed a profound shift in immigration policies in the last two decades, especially post 9/11, with a systemic expansion of immigration screening, controls, and border and interior enforcement (Mittelstadt et al., 2011). It significantly changed the socioeconomic and political landscapes that immigrants were living in. The time period chosen for this review would then reflect this shift in immigrant families and children's experiences. Third, we included studies that reported empirical data on predominantly immigrant families of children with IDD samples using various research methods. Lastly, we only included studies published in English.

We excluded studies that did not meet the above four inclusion criteria. Additionally, the following kinds of studies were also excluded due to our primary interest in empirical data: theoretical articles, government and organizational reports, conference abstracts and presentations, systematic/scoping/literature reviews, and prevalence studies.

Study Search and Selection

The final search was conducted on electronic databases using EBSCOhost with access provided by the University of Texas at Austin. Databases include SocINDEX, CINAHL, Health Source – Nursing/Academic and Consumer Edition, MEDLINE, PsycINFO, Education Source – Educational Administration Abstracts, ERIC, and Psychology and Behavioral Sciences Collection. The first set of search terms centered on [immigrant famil* OR child*], and second set incorporated a wide range of IDD including [intellectual disabilit* OR mental* retard* OR developmental disabilit* OR autism* OR Down* syndrome]. The third set of search terms rotated through health and healthcare-related services (e.g., health* OR healthcare OR medic* OR therap* OR insur*, and so on). The final search yielded 920 records. We imported these records into Rayyan, an internet-based application that allows systematic review researchers to collaborate remotely (Ouzzani et al., 2016). After removing duplicates, 665 records entered into the title and abstract screening phase. The first three authors independently performed title and abstract screenings using the 665 unique records to assess if they met the inclusion criteria with the blind review mode on Rayyan (Ouzzani et al., 2016). Once all three reviewers completed the reviews, the results were revealed and compared. Disagreements between any two of the reviewers were reassessed until a consensus was reached. Three reviewers yielded a 91.5% interrater agreement rate. As a result, we screened out 623 records. We identified additional records by going through reference lists of eligible studies and key researchers. We also went

through title and abstract screenings for these records. Eventually, 42 records from databases and eight records from hand-search moved into full-text screening. The full-text review yielded 26 studies that met all the inclusion criteria. Figure 1 presents the search and selection procedures.

[Insert Figure 1 about here]

Data Extraction and Reporting

We followed the PRISMA-P 2015 checklist (Moher et al., 2009; 2015) to extract data and report results. The authors performed data extraction with reference to Kilbourne et al.'s (2006) health disparity framework. Data from the included studies were recorded and categorized using the coding sheet. Each author then wrote a summary of the data source, sample, methodology, major findings, and other characteristics for each study. Lastly, the three reviewers compiled the results using the data extraction form for comparison. We then conducted final synthesis using the reporting framework outlined by Levac et al. (2010), and Bishop-Fitzpatrick and Kind (2017). The results from data synthesis are detailed below in the results section.

Results

Descriptive Statistics

Descriptive statistics were calculated for the included studies following the Campbell Collaboration Guidelines (Maynard et al., 2009; 2013). As shown in Table 1, the majority of the 26 studies had small samples (<50), were peer-reviewed journal articles, and were published between 2010 and 2020. Twenty-two articles reported the participants' level of acculturation using English proficiency or years in the US. We categorized level of acculturation into low and high. We defined low acculturation as having low English proficiency, a preference for their native languages, or having lived in the US for less than ten years at the time of the study. Twenty-one studies collected information on the participants' socioeconomic status (SES). We

categorized SES into two categories (low vs moderate-to-high), based on income or education (high school or less) reported by the original studies.

[Insert Table 1 about here]

The included studies' sample sizes vary, ranging from 10 to 413 for quantitative studies and 1 to 32 for qualitative studies. The total sample size of the included studies is 1,193. Twenty-one studies reported families' nativity. Of those reported, immigrant parents from Central and South America (including Mexico, $n=309$), and Asia ($n=127$) were the majority. We also calculated race/ethnicity composition based on data reported in the original studies. Latinos accounted for 72.5% of all participants, followed by Asians (10.6%), Blacks (5.8%), Whites (4.8%), and multi-race and others (4.4%). Table 2 summarizes key participant demographics.

[Insert Table 2 about here]

We synthesized findings based on Kilbourne et al.'s health disparity framework (2006). In summary, we classified five studies as detecting, 17 as understanding, and four as reducing disparities.

Detecting Disparities

Five studies (Lin et al., 2012; Lin & Yu, 2015; Magaña et al., 2013; Burke et al., 2016; Zuckerman et al., 2017) reported results related to detecting disparities. There were considerable variations in research questions, design, and sample sizes. Lin et al. (2012) examined the association between a family's immigration status and outcomes in healthcare service access and utilization using the 2007 National Survey of Children's Health (NSCH). They found that immigrant families were nearly twice as likely to express the need for care coordination and three times as likely to lack any kind of insurance coverage. They also found that immigrant

parents were twice as likely to report physicians not spending enough time with them, compared to their nonimmigrant counterparts (Lin et al., 2012).

Similarly, Lin and Yu (2015) found that although more children from non-English primary language households were reported to have a severe level of ASD, only 20% of them had private insurance compared to 44% of those from English primary language households. Burke et al. (2016) examined the differences between White and immigrant Latina mothers of children with ASD. They found that Latina mothers had less knowledge and felt less empowered in navigating the ASD service delivery systems. Magaña et al. (2013) compared diagnostic and specialty service utilization between 48 Latino and 56 non-Latino White children with ASD in Wisconsin. The results showed that Latino children from immigrant households received their diagnosis significantly later, had fewer specialty services, and greater unmet service needs than non-Latino White children. Zuckerman et al. (2017) surveyed families of children with ASD. They found that Latino families with lower English proficiency experienced barriers to knowledge about ASD and trust in service providers. Their children also received fewer therapy hours and had more unmet service needs.

It is also important to note commonalities across these studies. First, these studies compared immigrant and nonimmigrant families of children with IDD using quantitative survey data. Second, most of the immigrant subsamples were Latino families and children. These commonalities reflect the trend that Latino immigrant population has become one of the largest and fastest growing minority groups in the US (Pew Research Center, 2017). However, we did not identify any studies investigating service access disparities and barriers among other immigrant groups such as those from Asia.

Understanding Disparities

Seventeen studies focused on understanding determinants underlying disparities faced by immigrant families of children with IDD. Kilbourne et al. (2006) outlined different levels of factors that impact health disparity, which include patient factors, clinical encounters, provider factors, and healthcare system factors. Therefore, we categorized studies based on the levels of factors (Kilbourne et al., 2006).

Individual (Patient) Level Factors. Overall, knowledge/perceptions about IDD and services, personal resources, immigration status, and cultural considerations were the most salient individual factors identified by immigrant families of children with IDD.

Specifically, 11 studies (John et al., 2016; Sanchez, 2005; John & Bednar, 2018; Davies, 2018; Sakai et al., 2019; Novoa, 2015; Won et al., 2004; Jegatheesan, 2009; Blanche et al., 2015; Kwon, 2015; Bogenschutz, 2014) identified factors related to immigrant parents' knowledge or perceptions that were associated with disparities in service access and utilization. Immigrant parents were less likely to be well informed of IDD before their children's diagnosis (Sanchez, 2005; Davies, 2018; Novoa, 2015; Blanche et al., 2015; Bogenschutz, 2014). Although immigrant mothers often noticed signs of IDD as early as nonimmigrant parents, they were less likely to seek help from professionals due to a lack of knowledge and information (Sanchez, 2005; Novoa, 2015; Davies, 2018).

Personal resources such as family and social support affected access and utilization of healthcare services (Phelan et al., 2010; Magaña et al., 2013). In four studies, immigrant parents reported the impact of personal resources on service access and utilization for their children with IDD (John & Bednar, 2018; Sakai et al., 2019; Novoa, 2015; Zechella, 2014). Immigrant parents had to assume most caregiving responsibilities attending to their children's unique needs, partly because they lacked family and other social support given their emigration (Novoa, 2015).

Two studies explored the association between immigration status and service access and utilization (Mora-Lopez, 2016; Alvarado, 2004). Alvarado (2004) found that being undocumented affected every aspect of their families' lives, including lower family income and the lack of insurance coverage, resources, and services. Undocumented families of children with IDD were constantly living with the fear of being deported if they sought help from formal services through medical and school systems (Mora-Lopez, 2016).

Cultural perceptions and considerations were highlighted by four studies (John & Bednar, 2018; Sakai et al., 2019; Kwon, 2015; Yu, 2009). These considerations were especially evident among immigrant families from Asia. For example, Kwon (2015) and Sakai et al. (2019) reported that East Asian parents often felt a sense of guilt and shame for bringing a child with IDD to the world. As a result, they tended to hold responsibilities to themselves and were afraid of being seen as "incompetent" parents, which results in less help-seeking (Kwon, 2015).

Provider and clinical encounter factors. These factors include providers' knowledge, attitudes, bias, financial incentives, and patient-provider communication in clinical encounters (Kilbourne et al., 2006). The majority (10 out of 17) of the studies on immigrant parents of children with DD identified language and cross-cultural communication barriers as one of the greatest challenges (Sanchez, 2005; Mora-Lopez, 2016; Sakai et al., 2019; Jegatheesan et al., 2010; Novoa, 2015; Won et al., 2004; Jegatheesan, 2009; Blanche et al., 2015; Luong et al., 2009; Yu, 2009). Meanwhile, the lack of culturally competent providers and services (John & Bednar, 2018; Mora-Lopez, 2016; Jegatheesan et al., 2010; Jegatheesan, 2009; Blanche et al., 2015; Yu, 2009; Bogenschutz, 2014) led to perceptions of discrimination (Novoa, 2015; Alvarado, 2004), and inadequate communication/partnership between providers and parents (John et al. 2016; John & Bednar, 2018; Sakai et al., 2019; Jegatheesan, 2009; Yu, 2009). For

immigrant families of children with IDD, linguistically appropriate services, providers' understanding of immigrant cultures and experiences, and respectful communications were the most important factors that facilitated service access and utilization (Jegatheesan, 2009).

Healthcare system-level factors include service accessibility, coordination, continuity, and comprehensiveness that affect service utilization and outcomes. For undocumented families, their children's rights to receive services were compromised due to parents' immigration status (Mora-Lopez, 2016; Alvado, 2004). Even for families with legal status, barriers were systematically imposed by the healthcare system attributed to its complexity, English-oriented practices, and under-resourced service provisions. Language barrier exist across different healthcare and educational settings (Sanchez, 2005; Mora-Lopez, 2016; Sakai et al., 2019; Jegatheesan et al., 2010; Novoa, 2015; Won et al., 2004; Jegatheesan, 2009; Blanche et al., 2015; Luong et al., 2009; Yu, 2009; Bogenschutz, 2014). In addition, immigrant families often found it difficult to navigate the healthcare system due to limited information and support provided in their native languages (Won et al., 2004; Jegatheesan, 2009; Yu, 2009). Bogenschutz (2014) found that there were poorer services for immigrant families among different service providers. Additionally, evidence shows that services were under-funded (John & Bednar, 2018), and children's IDD-related service needs were delayed (Sakai et al., 2019; Mora-Lopez, 2016). The evidence from the included studies suggested that systematic barriers hindered service accessibility, coordination, and continuity for immigrant families of children with IDD.

Reducing Disparities

Research is emerging in developing and implementing interventions to reduce disparities (Kilbourne et al., 2006). We found four articles on reducing disparities through intervention for immigrant families of children with IDD. Burke et al. (2016) conducted a quasi-experimental

study to evaluate an intervention's effect on enhancing Latino families' knowledge of special education for children with ASD. The intervention group demonstrated significantly increased empowerment, special education knowledge, and stronger family-school partnerships (Burke et al., 2016). Another study compared the delivery modes of an intervention targeting Latino families of children with ASD: one group was led by an occupational therapist (OT), and the other was co-delivered by an OT and a promotora, (Latino community health worker who are themselves mothers of children with ASD) (Mirza et al., 2020). Results from this study showed that participants in both groups had increased child participation outcomes. However, only the group co-led by the OT and the promotora showed improvement in family outcomes (Mirza et al., 2020). The remaining two articles were based on the same two-site randomized control trials (RCTs), in which Latino families of children with ASD from two states received a culturally tailored parent education intervention delivered by promotoras via family visits. Results of the RCTs demonstrated that the culturally tailored intervention was effective in improving outcomes for both parents and children with ASD. Compared to control groups, parents in the treatment groups had significantly higher confidence of and frequency in use of evidence-based strategies; children whose parents were in the treatment groups received significantly more services and had increased social communication skills (Lopez et al., 2019; Magaña et al., 2020). These studies provided initial evidence on how disparities could be addressed at the individual level. However, we did not identify any study that addressed disparities in service use among immigrant families of children with IDD at provider or healthcare system levels.

Discussion

This scoping review synthesized existing knowledge about access and barriers to services for immigrant families of children with IDD in the US, based on Kilbourne et al.'s (2006) health

disparity research framework. We evaluated the content, methods, and findings of 26 studies that met the inclusion criteria and identified gaps in the literature. Overall, there are multiple-level barriers in accessing diagnosis and health services for children with IDD from immigrant families. Prominent barriers identified include language barrier, poor service coordination, and the lack of culturally competent providers.

Gap of Literature in Health Disparities Research Targeting Immigrant Children

Detecting Disparities

The lack of studies on detecting disparities is perhaps the most substantial gap in the literature. Only two studies were found. This gap may be due to the lack of large-scale studies purposefully recruiting participants from immigrant households. It may also be due to the lack of researchers focusing on immigrant populations (Maye et al., 2021). Even though children of at least one immigrant parent account for a quarter of all children in the United States (Urban Institute, 2019), national studies that do collect data on children with IDD often do not come close to a representative sample when it comes to immigration. Due to the immigrant population's diverse nature in terms of income, education, immigration history, English proficiency, and cultural beliefs, using non-representative samples increases the likelihood of drawing false conclusions. Nonetheless, the only two studies using national data had limitations in other ways. Neither of them reported information on parents' acculturation level (years parents have been in the US, or English proficiency). This is problematic since reporting acculturation level is critical in helping us understand which subgroup of immigrants are experiencing the most obstacles in access to healthcare services.

The scarcity of national studies with representative samples of immigrant families of children with IDD is a reflection of the challenges in recruiting immigrants, particularly those

who are racial minorities in research studies. Historical mistrust along with the lack of proactive community outreach and partnership building may have led to this population's hesitancy to participate in research studies (Martinez et al., 2012). Another potential factor is the negative image of immigrants created in political discourse and rhetoric and its potential damage on immigrant families' comfort level in joining research studies.

Understanding Disparities

The majority of the studies identified belong to "understanding disparities" under Kilbourn's three-phase framework. Most of the studies underscored healthcare system barriers, while fewer studies covered provider and individual level factors. This highlights the pressing need for interventions and policies targeting barriers faced by these families in a systematic way.

Furthermore, the included studies attempting to understand disparities have limits in their sample size and methodology. Out of the 17 studies, only two studies adopted quantitative methods using cross-sectional data. Although qualitative methods provide rich information on immigrant families' first-hand experiences, it is limited in examining causal pathways.

Additionally, all 17 studies had small sample sizes. None of the studies adopted longitudinal design, which may provide insights into how time and acculturation plays a role in understanding disparities. The lack of large sample studies and longitudinal studies may be due to the intensity of research effort required to translate materials, recruit participants, and engage with the population. Despite the challenges in conducting research studies with diverse immigrant populations, in order to pinpoint areas of intervention, we must investigate factors at all levels employing larger, more representative samples of immigrant families. Studies with larger sample size could also help inform policy advocacy efforts in better supporting immigrant families.

Addressing Disparities

The dearth of intervention and implementation studies reflect the nascent nature of the field. All four studies identified in our scoping review targeted Latino immigrant families of young children with ASD, examining the effectiveness of several parent education programs in reducing disparities. Future interventions should expand their focus to diverse immigrant communities of children with other IDD. Three out of the four studies had small sample sizes (Mirza et al., 2019; Burke et al., 2016; Lopez et al., 2019). The only large RCT intervention (Magaña et al., 2020) showed its efficacy in increased service utilization outcomes. We did not find any large-scale translational study.

The characteristics of these intervention studies showed a few recent and promising trends in intervention design and implementation for immigrant families of children with IDD. First, interventions that incorporated both parents and children were efficacious in improving both family and child outcomes. Second, interventions that employed lay health workers (promotoras) who speak the same language as the families were shown to be a cost-effective, feasible, and promising way to increase service accessibility for low-resourced families (e.g., Latino immigrant families in Magaña et al.'s RCT study). Third, these promising findings underscored the importance of future translational research to adapt interventions to address the disparities faced by diverse immigrant families of children with IDD.

Limitations of Kilbourne's Framework

As we presented the findings based on Kilbourne et al. (2006) 's framework, certain limitations of the model emerged. We noticed that certain factors placed under the individual patient level might be more appropriate under the healthcare system and provider encounter level. For example, Kilbourne et al. (2006) grouped race, ethnicity, and culture under individual

patient-level factors. However, literature has documented the limitations of placing race at the individual level rather than the structural level (Maye et al., 2021). Thomas et al. (2011) expanded Kilbourne et al.'s (2006) framework adding a fourth generation of health disparity research utilizing interventions to address issues on race, racism, and structural inequality. Although race plays an important role in the experiences of immigrant families of children with IDD, it is important to integrate cultural understanding as a tool for reducing provider level and healthcare level barriers. An intersectionality approach in understanding disparity may provide more context about the complex mechanism of multilevel barriers faced by immigrant families of children with IDD (Ben-Moshe & Magaña, 2014).

Implications for Future Research

What is Needed?

Overall, our findings have several implications for future disparity research on children with IDD from immigrant families. First, we need more datasets that identify immigrant families and more researchers examining the disparities between immigrants and nonimmigrant families of children with IDD. Second, few studies included key variables such as English language proficiency, acculturation, socioeconomic status, and parents' education level. Future studies should consider including this information to help researchers identify which subgroups are facing the most adverse barriers given the diverse nature of the US immigrant population (Budiman, 2020). Third, we only found two studies examining barriers faced by undocumented immigrant families of children with IDD. The challenges faced by undocumented families under the current political atmosphere are often compounded with strict immigration policy and rhetoric against immigration. Given the small sample size of these two studies, we cannot have a thorough understanding of how immigration policy and discrimination impact their access to

critical health services and how to effectively address the barriers faced by undocumented families. Furthermore, the dearth of intervention studies geared towards this population is alarming. Particularly, researchers should further intervention studies for this population by scaling up, implementing, and evaluating evidence-based interventions to address barriers facing this population on a larger scale.

How to Enhance Research for this Population?

Although researchers in the past two decades have synthesized ways to effectively recruit and retain minority participants in research (Maye et al., 2021; Yancey et al., 2006), there is a scarcity of research documenting components needed in a study to detect, understand and reduce the health disparities facing immigrant participants. Though this topic is worthy of a separate and focused scoping review, we summarized a few critical elements based on our review. First, since language barrier is one of the most commonly identified barriers to healthcare (Sanchez, 2005; Mora-Lopez, 2016; Sakai et al., 2019), large national surveillance studies should ensure language accessibility of study instruments, outreach materials, and have interpreters or bilingual staff available to support the process of participation. Second, flexible study design such as using family visits instead of clinic-based intervention mode of delivery could be a viable way to improve participation and retention, particularly for intervention and longitudinal studies (Lopez et al., 2019; Magaña et al., 2020; Mirza et al., 2020).

Another approach to enhance recruitment and retention is to involve key community stakeholders or community organizations in study recruitment and implementation of interventions (Lopez et al., 2019; Magaña et al., 2020; Martinez et al., 2012; Kuhn et al., 2020) to obtain trust and eliminate fear (Mora-Lopez, 2016). Sustained community presence instead of periodic research activities can help build the long-term relationship between community

stakeholders and researchers (Maye et al., 2021). Methodologies such as community-based participatory research or participatory action research could enhance community members' participation in the process of intervention design (Vaughn et al., 2017; Magaña et al., 2021).

As researchers conduct health disparity research with this marginalized and hard-to-reach population, more "lessons learned" commentaries are needed to expand the knowledge on how to conduct research studies with this population.

Limitations

The scoping review has a few limitations. First, due to the scarce literature on our target population, we could not conduct an in-depth evaluation of the quality of evidence. Second, we limited years of publication in our search, which may result in an inability to incorporate historical contexts and shifts in immigration policies. Lastly, due to the lack of studies that reported information on immigration history and acculturation, we employed a relatively rough standard for our definition of acculturation using English proficiency and years in the US. Such definitions can be problematic when drawing conclusions on immigrant families with diverse acculturation experiences.

Conclusion

While existing evidence suggests that immigrant families face multiple levels of barriers when accessing services and care for their children with IDD, we know relatively little about the disparities facing this population. Although evidence of disparities using large national samples has only recently emerged, such evidence and the fast growth of children of immigrant households indicates the need to expand our knowledge on detecting, understanding, and reducing disparities. Given that barriers to services have been documented consistently in existing literature, a few critical steps for future research are needed. Specifically, there are

pressing needs for future studies to 1) continue understanding the mechanisms of different levels of disparities using more representative samples to inform interventions and policy; 2) expand the knowledge based on the framework of Kilbourne et al. (2006) 's health disparity research; 3) design and evaluate interventions targeting provider and healthcare system-level barriers.

Through these efforts, we can expand our knowledge on barriers and disparities faced by children with IDD from immigrant families and develop innovative interventions to address such disparities.

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Figure 1

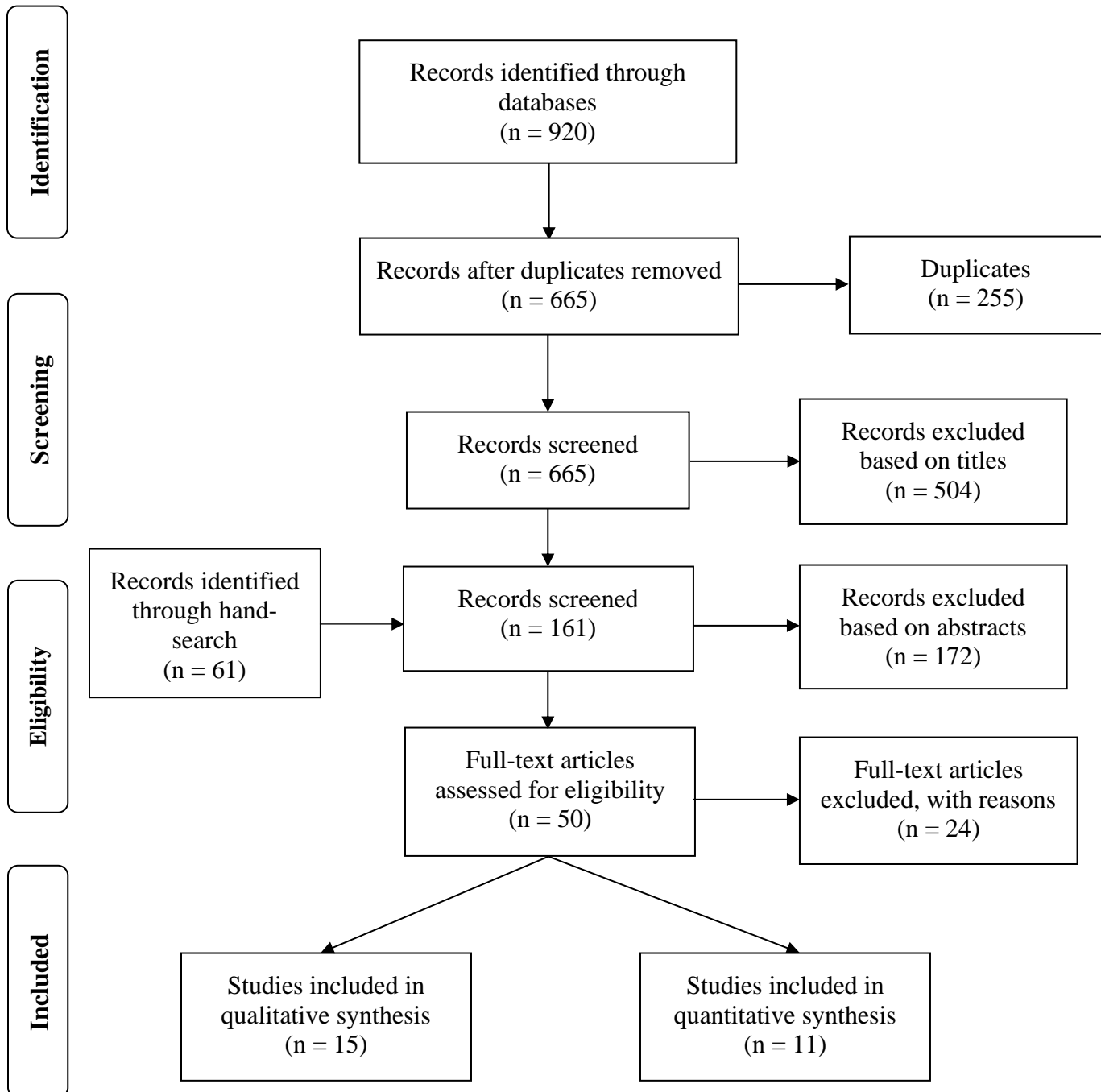
PRISMA Flow Chart

Table 1*Characteristics of Included Studies*

Characteristics	Quantitative (N = 11)	Qualitative (N = 15)
	n(%)	n(%)
Publication year		
2000 - 2009	1(9)	5(33)
2010 - 2020	10(91)	10(67)
Publication type		
Journal article	10(91)	9(60)
Dissertation/thesis	1(9)	6(40)
Sample sizes		
1 – 25	2(18)	13(87)
26 – 50	4(36)	2(13)
51 – 100	3(27)	--
>101	2(18)	--
Level of acculturation		
Low	7(64)	9(60)
High	1(9)	5(33)
Not specified	3(27)	1(7)
Socio-economic status ^a		
Low	10(91)	3(20)
Moderate to high	1(9)	7(47)
Not specified	--	5(33)

Note. ^a A study was categorized as having low SES participants if more than 50% of the participants had less than a high school education or an income of less than 200% Federal Poverty Level.

Table 2*Demographic Characteristics*

Characteristics N=1,193	Quantitative	Qualitative
	n(%)	n(%)
Parent nativity ^a		
Asia	33(3.2)	94(54.0)
Central and South America	291(28.6)	18(10.3)
Africa	--	31(17.8)
Not specified	694(68.2)	31(17.8)
Race/ethnicity		
White	57(5.6)	--
Hispanic/Latino	832(81.7)	33(19.0)
Asian	33(3.2)	94(54.0)
Black	38(3.7)	31(17.8)
Multi-race and other	52(5.1)	--
Not specified	6(0.1)	16(9.2)

Note. ^a Asian parents' countries of origin: India (54), China (42), South Korea (8), others (23); Central and Latin American parents' countries of origin: Mexico (245) and others (64).



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Supplemental Material

Table 4 Overview of included studies.docx

