

**Intersectional Challenges within Immigrant Families with Children with Developmental  
Disabilities**

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## **Abstract**

This qualitative case study examined the intersectional challenges human service workers observe when working with immigrant families with children who have Developmental Disabilities (DDs). In-depth interviews were conducted with Central Valley Regional Center and Child Welfare workers. Participants in this study identified the intersectional challenges this population faces. This study generated knowledge and a deeper understanding of the many intersectional challenges immigrant families with children who have developmental disabilities face. Implications to better serve this population were discussed.

Keywords: Immigrant Parents, Developmental Disabilities, Intersectional Challenges, Children, Barriers.

## **Intersectional Challenges within Immigrant Families with Children with Developmental Disabilities**

Developmental Disabilities or DDs refer to groups of disabilities that arise as a result of an impairment in behavior, physical, language or learning areas (Center for Disease Control and Prevention, n.d). It is during the developmental period that these conditions begin to show (Center for Disease Control and Prevention, n.d). DDs could significantly affect the day-to-day functioning of an individual, and in certain instances, they could last throughout an individual's lifetime (Center for Disease Control and Prevention, n.d). Even though the term developmental disability is one that people hear throughout their lifetime, few comprehend the whole spectrum of what it entails. The reality is disability does not discriminate and can happen to anybody. For any parent, it is heartbreaking to learn that a child is struggling with a developmental milestone such as waving "bye" or taking that fulfilling first step. Even though children's development varies by child, they are often expected to behave in a certain way after reaching a certain age. This is what points to developmental delays. Those affected struggle in areas such as language, independent living, learning and self-help.

Intersectionality theory sheds light on how much more difficult and challenging it is for immigrant families to access services like healthcare. Intersectionality theory, first coined by Kimberlé Crenshaw, is often used to describe the oppression of minorities who intersect various systems such as race, ethnicity, age, and class among other factors (Slaughter & Saintil, 2020). This paper uses intersectionality theory to describe how immigrant families with children with developmental disabilities face tremendous amounts of barriers and challenges. This has been an ongoing issue because families are facing extreme difficulties when seeking services due to these barriers and challenges that can include cultural stigma, immigration status, language barriers,

literacy, stereotyping, socioeconomic status, and many forms of stressors. Intersectionality perspective provides a deep understanding of how immigrant families with children with developmental disabilities interact with these systems where they are subjected to social injustice and discrimination (Pang et al., 2020).

Those who are of a minority status like an immigrant tend to experience higher rates of discrimination when accessing services like healthcare (Pang et al., 2020). Systems of oppression in the healthcare system are inherently bound together, and they work to the disadvantage of minorities. For these minorities, health challenges like racial inequality are not isolated cases. Institutions should have the ability to recognize that there are certain social issues that have systemically discouraged the efforts of immigrants to get quality care.

Young & Crankshaw (2021) stated that in the United States, over three million children have a disability. As of 2019, over 44.9 million immigrants were living in the United States. Immigrants who reside in the United States have children with disabilities (Batalova et al., 2021). A large number of immigrants may have children with some form of developmental disability. All things considered, it is important to acknowledge that the immigrant population has increased as well as those who are born with some developmental disability. This is an ongoing problem that affects millions of families across the United States.

Even though there are still gaps in the literature surrounding how intersectionality overlaps with developmental disabilities, what remains certain is that the issue of health disparity is pervasive, and it is immigrants who are most affected. In 1975, the Individuals with Disability Education Act (IDEA) went into effect that allowed millions of children to receive appropriate education and ensured special education along with services for those who qualify (Department of Education, n.d). Even though the IDEA provided educational services for children with

disabilities, they did not address how difficult it can be to navigate the educational system for immigrant families (Arfa et al., 2020; Cortez, 2020; Cycyk & Duran, 2020; Dijkstra, & Rommes, 2021; Khanlou et al., 2014; Lim et al., 2020, Lindsay et al., 2012). This affects immigrant families, families who are not familiar with the IDEA, first-time parents of a child with developmental disabilities, and individuals with disabilities.

Research has shown that immigrant families are struggling to navigate the systems their children interact with (Dijkstra, & Rommes, 2021). At times, they are reluctant to seek services because of their immigration status (Vargas & Pirog, 2016). Vargas & Pirog (2016) found that undocumented immigrants fear going to the physicians for fear that they will notify immigration authorities. Moreover, research has concluded that immigrant families are reluctant to face the many questions professionals ask. For this reason, they would rather not engage in services that would benefit their children (Sidhu & Song 2019). Studies have shown that comorbidities are more likely to develop for parents who have children with DDs (Kim & Kim, 2007; John, 2016; Pang et al, 2020; White, 2004).

While there has been research on immigration barriers, further research needs to be done on how these barriers affect immigrant families living in rural areas. Further, studies should be conducted on what education is given for families that are afraid of seeking services, and the risk of deportation for program use. In the Central Valley, California, there are half a million children with at least one immigrant parent. Central Valley, also has large rural communities with high number of immigrants (Immigration in the Central Valley - CVIIC, 2022). However, there is hardly any research on intersectional challenges of immigrant families with developmental disabilities. Research is especially sparse when it comes to human service perspectives on challenges. Further research is needed to determine the gaps within the intersectional challenges

immigrant families face in the Central Valley, especially from human services workers as we attempt to assist these families. Consequently, this study looked at the intersectional barriers faced by immigrant families of children with developmental disabilities in the Central Valley. The study focused on human service worker experiences in helping these families get help.

### **Literature**

Intersectionality was first coined by Kimberlé Crenshaw. It can be described as social identities, systematic social inequalities, and disadvantages that are legitimized by those who hold power (Slaughter & Saintil, 2020). Intersectionality is a framework that asserts that individuals are ordinarily disadvantaged by numerous sources of oppression. The oppression that they face could be due to their race, religion, class, sexual orientation, or any other identity markers. It considers the overlapping experiences and identities of individuals as a way of understanding the complexity of the prejudices that they are subjected to. Intersectionality underlines the fact that all oppression is linked in some way. It acknowledges the fact that people have unique experiences of oppression and discrimination. Intersectionality appreciates the fact that identity markers such as one being “black” or “woman” are dependent on each other, and they work to create a convergence of oppression that is complex (Santovec, 2017). This explains why women of color have often been discriminated against in their places of work even though they perform similar tasks as their white counterparts. By understanding intersectionality, it becomes easier to address the interwoven prejudices that women of color face (Santovec, 2017; Slaughter & Saintil, 2020).

Intersectionality provides a better understanding of the complexity and oppression diverse families with children with Developmental Disabilities (DD) face. When working with diverse individuals and families, it is vital to take every intersecting identity and experience into

account (Pang et al., 2020). Individuals with DDs intersect a variety of systems such as ethnicity, gender, race, and disability. Intersectionality theory provides a better understanding of how these systems interact, as well as how they can cause social injustice and discrimination (Pang et al., 2020).

In the United States, there are many programs provided to assist families with children with DDs. The Individuals with Disabilities Act (IDEA) is a special education and early intervention program to assist children with disabilities (Dragoo, 2018). This act was an accomplishment brought to the communities by parents who wanted an opportunity to see their children thrive. In the United States, there are over three million children who have a disability. This number has increased by 0.4 percent since 2008 (Young & Crankshaw, 2021). However, what is rarely talked about is the intersectional challenges unique families face. For example, families that come from different cultural backgrounds, many of which face many challenges due to their immigration status (Brassart et al., 2016; Cortez, 2020; Cycyk & Duran, 2020; John & McCullough, 2016; Lim et al., 2020; Lindsay et al., 2012; Slaughter & Saintil, 2020).

In 2019, more than 44.9 million immigrants lived in the United States (Batalova et al., 2021). Numerous immigrant families have children with developmental disabilities and are struggling to navigate the systems that are in place to help their children succeed (Arfa et al., 2020; Cortez, 2020; Cycyk & Duran, 2020; Dijkstra, & Rommes, 2021; Khanlou et al., 2014; Lim et al., 2020, Lindsay et al., 2012). Immigrant families face unique barriers when seeking services for their children with DDs. These can include cultural stigma, immigration status, language barriers, literacy, stereotyping, socioeconomic status, and many other forms of stressors.

When children with developmental disabilities attain the age to attend school, immigrant families frequently interact with the school system. At times, parents only know what doctors or psychologists have shared with them about the diagnosis. Most of the time immigrant parents have a difficult time comprehending the literacy of diagnosis. Immigrant families are having to meet with health care professionals often depending on the diagnosis of the child. The mass majority of times, parents are not educated on the diagnosis itself and how to assist their children throughout their development.

Health literacy is important when communicating with medical professionals. This means understanding basic health information or what treatment or services will be provided to the child (Lim et al., 2020). This is a disadvantage to immigrant families since they do not have prior knowledge or education of the diagnosis. Most of the time, immigrant parents receive a brief education of the diagnosis when the evaluation is completed. This could easily confuse immigrant families regarding services (Brassart et al, 2016). Lindsay et al., (2012) suggested that health providers should provide immigrant families with services and resources available to them. This can include support groups within the community. However, Afra et. al (2020) stated that at times, health professionals are not aware of services available to families with children with developmental disabilities.

An Individualized Education Plan (IEP) is a legal document that states the child's developmental disability along with goals and objectives developed for the child by educators who are assisting with the child's learning ( Lim et al., 2020; Cortez, 2020). Immigrant parents often struggle with the education system due to the language barriers between service providers and parents (Arfa et al., 2020; Brassart et al, 2016; Cortez, 2020; Cummings & Hardin, 2017; Dijkstra & Rommes, 2021; Durà-Vilà & Hondes, 2009; Khanlou et al., 2014; Kim & Kim,



2017; Lim et al., 2020; Lindsay et al 2012; Lindsay et al, 2014). Most immigrant families are not proficient in English and this affects how they interact with educators or healthcare professionals.

Research has shown that language barriers have made it challenging for parents to receive information about their child developmental disabilities and services that are available to them (Durà-Vilà & Hondes, 2009). The language barrier often discourages parents from advocating for themselves and their children (Lim et al, 2020; Lindsay et al, 2012). It is also important to note that Spanish does not translate to English with the same meaning. This means that at times, immigrant parents' concerns, problems, feelings may not be translated how they are meant in the English language. Information can be misinterpreted and this can cause difficulties in accessing adequate services (Khanlou et al., 2014). Nonetheless, immigrant parents spend less time communicating their ideas or opinions to educators assisting with the needs of their child. Parents with normally developed children tend to spend time advocating for their children since they can converse about the issues or concerns they may have.

This can potentially cause parents to find it challenging to advocate and then be disengaged in their children's progress (Brassart et al., 2016; Dijkstra et al., 2021; Lim et al, 2020). Individuals with developmental disabilities are often judged and highly stigmatized (Dijkstra, & Rommes, 2021; Chiu et al, 2013). Cultural stigma has also played a significant role in immigrant families with children with developmental disabilities; this can include social stigma and shame (Chiu et al, 2013; Dijkstra, & Rommes, 2021; Pang et al, 2020; Lindsay et al., 2014; Su et al., 2018). Oftentimes, parents are struggling to cope and accept the fact that their child has a disability (Zechella, & Raval, 2015). Immigrant families worry how their child will be perceived in their culture. Due to the cultural perception of the disability, some mothers can

become hesitant on whether to seek services for their children (Khanlou et al., 2014; Durà-Vilà & Hondes, 2009). In some cultures, immigrant parents believe that their children grow out of it or be cured of it (Durà-Vilà & Hondes, 2009). In some Chinese cultures, it can be related to something the mother ate (Chiu et al, 2013). It is also important to consider the fact that in some cultures, families take on the caretaker role instead of aiding them to be independent (Pang et al., 2020).

Research has shown that mothers often develop anxiety or depression when their children are diagnosed with developmental disabilities (Kim & Kim, 2007; John, 2016; Pang et al, 2020; White, 2004). Mothers with children with developmental disabilities have higher stress levels compared to other children (Brassart, 2016; Chiu et al, 2013; Cortez, 2020; Cycyk, & Durán 2020; Durà-Vilà & Hondes, 2009; Change et al., 2018). Chiu et al. (2013) posit that a lot of this stress stems from being devalued by others, thus leading to poor self-esteem and mental health. Immigrant parents can get extremely stressed in their quest to understand the language of their children's diagnosis as well as the lack of support (Kim & Kim, 2007; Zechella, & Raval, 2015). This can potentially push them to isolate from society due to the social stigma. Immigrant parents often feel as if they are being treated unfairly (Arfa, 2020). Pang et al., (2020) stated that past literature has demonstrated that minority groups experience discrimination when accessing services available to them such as healthcare and education.

Mental health is frequently disregarded and stigmatized among immigrants. As a result, many immigrant families experience excessive stress. According to Lopez and colleagues (2018), persons with less education are less likely to access services. This is due to the cultural stigma that mental illness and are scared to seek help because they don't want their relatives to think they're insane, according to both Ishikawa et al. (2010) and Lopez et al. (2018). An area

that is not being discussed is the intersection of culture and undocumented status to why immigrant families are reluctant to advocate for themselves and their children (Lindsay et al., 2012). It is important to note that undocumented families may not be aware of the resources available to them. This can be because in their native country, they did not have services that aided their children in development (Pang et al 2020). However, Sidhu & Song (2019) explain that at times, care providers ask parents questions which make them become fearful due to their immigration status. These authors explain that it is in the best interests of service providers not to push services on this group of people since they may become more resistant to receiving them. Frequently, it has to do with language barriers and the lack of cultural humility that has made it difficult for families receiving services (Pang et al 2020; Sidhu & Song, 2019).

Families are just starting to get educated on their children's disabilities, and it can be a lot for the family to process. There is a misconception and lack of understanding with the written resources on the disability. This can be overwhelming for parents and can create barriers to receiving services. Additionally, there is the fear of being undocumented and not wanting to receive aid for their children. Many families are afraid of the consequences of obtaining government assistance, believing that it may result in their deportation or interfere with their application for permanent residency (Vargas & Pirog, 2016) .

A study by Vargas & Pirog (2016) stated that Mexican families are more sensitive with service usage due to deportation. Cycyk, & Durán (2020) also stated that when parents or caregivers are deported, children with developmental disabilities are negatively affected. This can include loss of sleep, anxiety, withdrawals, symptoms of mental health, etc. (Cycyk, & Durán, 2020). Children witnessing their parents being deported can be transgenerational and cause future problems. Sidhu & Song (2019) stated that the arrest or deportation of parents

worsen their economic hardship. Children with DDs have more complex demands and require more time and resources to help them develop. The majority of undocumented immigrant families are working-class, which means that they must work to support their family (Cycyk & Durán, 2020).

Undocumented families often live in poverty and have low paying jobs with no benefits (Sidhu, & Song, 2019). They also have a more difficult time obtaining proper housing, transportation, and adequate resources (Cycyk, & Durán, 2020). Oftentimes, families are misjudged and are perceived as mistreating or neglecting their children because they are not taking them to service. Nevertheless, all immigrant families, not just undocumented immigrant families face economic constraints that can that can make seeking and receiving services difficult.

### **Method**

The purpose of this study was to explore the experiences of human services workers to identify the intersectional challenges immigrant families with children with developmental disabilities. Specifically this study looked at:

What do human service workers observe as intersectional challenges when working with immigrant families of children with developmental disabilities?

### **Research Design and Rationale**

This study employed a qualitative research approach as it allowed for access to information of a hidden population. It is grounded on human experiences that provide valuable results (Nowell et al., 2017). This qualitative approach aligned well with the purpose of this study, which is to explore the natural social life of the lived experiences of human service workers who have worked with immigrant families with developmental disabilities (Saldana,

2011). To show a proper representation to the complexity of challenges and barrier immigrant families with children with developmental disability a qualitative approach is best suited (Saldana, 2011).

Qualitative research allowed the researcher to explore the silent barrier human service workers have experienced through their scope of work. In qualitative research the researcher is the primary data collector instrument ((Nowell et al., 2017, Saldana, 2011). To fully understand the lived experiences of human service workers, in-depth interviews were conducted. Interviews can vary from one individual to a group. In this study, participants were interviewed individually via zoom, followed by a coding process. Throughout the coding process the researcher identified detailed analysis of the data that was most based on exploring (Nowell et al., 2017).

Specifically, phenomenological study design was used to conduct one on one interviews to collect data on the intersectional challenges immigrant families with children with developmental disabilities face through the lived experiences of human service workers. By using this study, the researcher gained detailed insight on the phenomena (Berber & Acar, 2021). This method allowed for flexibility in exploring deeper experiences within each participant. Phenomenology allows participants to express their feelings and concerns regarding their lived experiences. It also provided different viewpoints on the phenomena and compared the lived experiences between participants (Berber & Acar, 2021). This method allowed flexibility in exploring deeper experiences within each participant. Using this approach to understand the intersectional challenges with immigrant families, developmental disabilities allowed access to valuable information to help aid families in the Central Valley.

**Subjects** The sample frame for this study was only accessible for human service workers who have encountered challenges when assisting immigrant families with children with

developmental disabilities in the Central Valley. The inclusion criteria was further narrowed to human services workers from the Central Valley Regional Center (CVRC) and the Child Welfare. This allowed two different agency perspectives of the intersectional barriers and challenges. Therefore, making it only available for those that meet these criteria and excluding those who do not.

### **Sampling**

Purposeful sampling was the design used, with participants being selected based on the characteristic of information related to the phenomenon of interest (Palinkas et al., 2013). These individuals were selected because they have knowledge and experiences working with the population being studied. Moreover, snowball sampling was used to identify others who have shared experiences working with immigrant families with children with developmental disabilities (Yingling & McClain 2015). Given the nature of the sensitive and difficult to find population, the researcher asked program managers to help connect human services workers who may meet the criteria. Within this criteria once the parameters of sampling frame were identified, and purposefully the initial participants were selected, the author also utilized snowball sampling approach. Once meeting with a few participants snowball sampling was used to locate more participants (Yingling & McClain 2015). The author asked the existing participants if they could refer other participants who met the criteria.

### **Instrumentation and Data Collection**

Prior to the interviews, participants were emailed an informed consent form together with a demographic form to determine and distinguish the population being studied. The demographic form provided the researcher with information on the participants' ethnic background, gender, age, relationship status, county of residence, employment status, and level of education. .

Semi-structured interviews were determined to be the best method to obtain the perspective of human service workers' experiences with intersectional challenges immigrant families with developmental disabilities face. The nature of semi-structured interviews allowed participant opinions to be explored with some amount of structure. They also give the interviewer the ability to probe for more information, clarify interesting and relevant issues, and explore sensitive topics with some amount of flexibility. The focus was on the interpretation of the results that was based on the research objectives.

The interviews consisted of eight questions having more subsections as follow up questions and lasted for about 30-60 minutes . The sample frame for this study was accessible to about twelve (12) human service workers serving immigrant families having children with developmental disabilities. An online platform was used for the interview with Zoom, Facetime, Skype, Google Hangouts, and other digital platforms being preferred. Before starting the interview, the researcher requested a recorded audio granting permission to interview the participant. Next, the researcher confirmed that the consent form and demographics were filled out prior to starting the interview. The recording only contained the interviewees name and recording of the interview. The information collected on the participants was placed in a secure location inaccessible to anyone. To reinforce this, the recordings were kept in a password protected computer which was to be destroyed once transferred. IRB permission was obtained from Fresno State, prior to starting.

### **Data analysis**

The researcher read through the transcribed interviews and gave an insight to what they said. After transcribing, the researcher coded and concentrated on selected categories and finally determined the different themes that emerged placing them on a chart beginning a thematic

analysis. The coding process allowed the researcher to simplify and characterize specific data (Nowell et al., 2017). Once the coding was completed the codes were extracted by reorganizing and categorizing similar themes (Saldana, 2011 p. 26). Themes are identified as bringing together lived experience, in this study participants talked about their experiences and shared common themes (Nowell et al., 2017). The method provided for an analysis and organization of the data and for the key themes to emerge (Nowell et al.,2017). Notes were taken of statements to be used as quotes.

### **Reliability/Validity**

Reliability shows data adequacy or confirmability in a qualitative investigation (Coleman, 2021). Through multiple coding, also known as “peer review” or “consistency check” reliability was ensured by an additional qualitative researcher. By member checking the researcher confirmed what the participant stated during their interview (Coleman, 2021).

Validity refers to the appropriateness of the study on what it claims to inform (Coleman, 2021). The in-depth interviews also included voice memos and video recordings depending on how comfortable the participant was. The researcher transcribed these interviews verbatim. Interpretation of qualitative data was then done, and it painted a clear picture of the similarities and differences of the data (Coleman, 2021). Prolonged engagement, peer debriefing, member checking, auditing, and negative case analysis were addressed. The prolonged engagement with peers allowed for a trusting relationship where participants felt comfortable enough to share the whole truth throughout the 30 -60-minute interview. Peer debriefing then followed through engagement of colleagues that were not part of the project but doing a similar qualitative project. Also, a faculty member was also consulted for guidance with data themes emerging.



Categorization of the different themes allowed for the researcher to follow the research procedure through the provision of coding, analysis, and the decision-making process.

## Results

The primary purpose of this qualitative study is to understand the complexity of the intersectional challenges within immigrant families with children with developmental disabilities. Five themes emerged along with four sub-themes which helped answer the research question: What do human service workers observe as intersectional challenges when working with immigrant families of children with developmental disabilities? This section will present the demographic data and the following five themes that were identified through thematic analysis: language barrier, navigating while undocumented, lack of education or understanding of services, cultural barrier, resource deficiency that were followed by sub-theme including: financial barrier, services, transportation, and housing.

### **Demographic Data**

The researcher interviewed twelve individuals who met the required criteria. Eight of the participants were females and four were males. Nine of the participants self-identified as Latino or Hispanic, one self-identified as Asian, one self-identified as Black or African American, and one self-identified as Central American. Five of the participants reported to be between the ages of 46-60, the other five reported to be between 31- 45, and two of the participants reported to be between 16-30. Eight of the participants reported their relationship status to be single (never married, 3 are married, and one is divorced. Ten of the participants stated to reside in Fresno County the other two reside in Tulare County. All twelve participants reported working 32 hours and above. Six of the participants reported having a bachelor's degree and the other six reported having a master's degree.

## **Language Barrier**

The first theme to emerge was consistent throughout all participants. All participants reported language barriers to be an issue across all systems and not only in their agencies. It is important to note that language was not only an underlying factor between the client and agencies, but also the client and the human service worker. A concern that was shared across human services workers was that they did not know how to speak the native language of the client. A CVRC worker stated, "it can be a challenge because I don't know if what I'm saying is being conveyed to them the exact way, or vice versa." Another CRVC worker stated, "The wife has to speak to the husband and the husband speaks to me... I know a lot more is being said and it's probably along the lines of don't say this, ok I'll tell them this, so by the time I get the information, it's second hand." There are times agencies do not have a translator on-site when families arrive at their appointments or are seeking services. A child welfare worker stated, "The language barrier, you know mom couldn't communicate with the school, the school can't communicate with mom... the school is always telling you oh sorry we don't have anyone to translate... So, mom's been turned down a lot." This quote demonstrates that mom does not have access to the services because no one is able to communicate with her. Despite having services available to families, it is difficult to provide services in their native language. A CVRC worker stated, "When working with Spanish speaking families, in this case, it's just hard to find services in their language ... Even though we have a lot of vendors that provide services, we have a lot of vendors that don't speak their language."

This causes families to try to find their own interpreters. A lot of the time it is their children who are way too young to translate. A CVRC human service worker stated, "Sometimes they have the little kids translating... That is not the best translation, but they did what they could

basically.” Due to the lack of representation of agencies parents are having to have their young children translate, a lot of the time information can be misinterpreted. Even when agencies have interpreters, the information being translated may not be translated correctly. English does not translate directly to Spanish and vice versa. A CVRC worker stated:

You know I myself I'm bilingual and sometimes sitting in those meetings I'm like that's not the correct translation... I will intercept and explain to the family that this is what should have been translated... Whereas the parent is trying to say something, and it doesn't translate equally to what it would be in English, you're like well that's not correct.

### **Navigating while Undocumented**

Workers also talked specifically challenges experienced by undocumented families, or families with mix status with at least one member being undocumented. In the Central Valley, there is a large population of undocumented non-citizen immigrants. The fear of their information being released to immigration is altogether real. A lot of times, the fear of deportation is a major reason undocumented immigrant families do not seek services. A child welfare worker stated:

We tell them about these agencies, and they automatically are concerned or worried as to know where they are sending me to? Who am I going to be talking to? What if they ask me for this information and I don't have that? So, they definitely go with the fear and sometimes don't go to these agencies I refer them to because ... they may get deported.... Child welfare is a government agency program a lot of the time they think we work closely with immigration. They feel like we pass on their information... we have to educate them that's not the situation we don't work with them.

A large number of immigrant families in the Central Valley have at least a friend or family member that is not documented. Sometimes, even if majority of the family is documented they may have at least one family member or friend who is undocumented living with them. Workers talked about how these families are fearful that they will get asked questions they don't want to provide answers to. A child welfare worker stated,

Even though they know what services they want and what they need they won't disclose that information because they have people living with them that are undocumented and they don't want the authorities coming over and finding them and getting deported or them getting in trouble.

This quote demonstrates that immigrant families are afraid of seeking services because most families live in multifamily settings who are also immigrants and do not want to jeopardize their status or get in some trouble. It is important to acknowledge the constant fear these families face, immigrant families are not familiar with child welfare and are unsure with how the agency works. This is a common stressor amongst families, aside from having to work with agencies that they are unfamiliar with but must to help their child's DD.

A child welfare worker stated, "They are scared to apply for services or Medical because they're scared that they can get deported or make some type of influence and their immigration status." The fear of using services and public assistance in a way where it will affect them later when attempting to legalize their status was an everyday fear. Another common issue is that some agencies can be unwelcoming and make it difficult for families to seek services. A CVRC worker stated "sometimes agencies are rude and say stupid things to them like well you're not even a citizen... I had someone say to a family you should get deported." Immigrant families are

already going out of their comfort zone to seek services for their child who has a DD. Making threats to them like “you should get deported” only makes things more difficult and challenging.

Being undocumented in America can be extremely difficult but it is more challenging to be undocumented and have a DD. This next quote addresses the children who were both undocumented and had DD and were unable to receive services because of their double status. A CVRC worker stated, “she has medical physical limitations as well, but because she's undocumented ... they're not eligible for in-home supportive services.” Many children who are undocumented are not able to access services that would help their well-being.

The other side of this equation is that since they are not eligible for services, sometimes child welfare system is the only way to get the needed services. A child welfare worker talked about how a family was so desperate to get services for her child that she made a child protection report on herself because she was unable to care for her child. The child welfare worker stated, “they couldn't cover them because a child was not a dependent of the court we were trying to work with the family before we got involved, but because the child was undocumented, they couldn't apply for Medi-cal.” The child welfare worker expressed that no one wants to have a CPS report, but the mother was able to obtain services for her child and was relieved to have called CPS on herself. Emergency Medi-Cal is available to the undocumented population, however, does not cover every medical treatment. A CVRC worker stated, “There used to be a special medical that the child could have, but you know services are expensive if you're seeing a specialist like a neurologist...She doesn't qualify for social security, because she doesn't have documentation.” Despite there being emergency Medi-Cal, families are still having to pay for some services out of pocket that emergency medical does not cover. Therefore, leaving this population without coverage and services. Nevertheless, undocumented children with DD cannot

apply and acquire access to social security due to their immigration status. This makes it extremely difficult for families to receive support and figure out a way to sustain themselves.

### **Lack of education or understanding of services**

Throughout interviews, it was noted that there is a general lack of education or understanding from the parents' side as to where they can seek services. Parents are still trying to adjust and process the diagnosis. A CVRC worker stated:

um you know some families weren't accepting of the disability, you know or didn't have the knowledge or understanding of it and then, sometimes they themselves don't understand what the help is all about, especially with those who are receiving autism services, ABA (Applied Behavior Analysis) services because it does take parent involvement and getting them to buy into the treatment plan and sometimes they don't follow through because they just don't understand.

ABA requires a lot of parents involvement; immigrant parents have a difficult time adjusting to the changes ABA requires them to. Another CVRC worker stated:

They need more time for things to be explained to them because they're processing and everybody's process is different and they may need to be told, maybe more than once, maybe several times repeating information as they need it, and if they still don't get it it's okay repeated again...

Families must be given the time to process their emotions through this life journey. With a new diagnosis comes the many agencies and services immigrant families must interact with. A CVRC worker stated, "...it's a lot of educating the families about the process and what services

are out there.” Participants stated that they must educate the parents on the services available to them. There are times when human service workers are having to speak on the parents’ behalf because it is challenging for them to navigate services independently. Participants also spoke about their own limitations. This was common amongst child welfare workers who are not experienced with children with DD. A child welfare worker stated, “You know we don't encounter a lot of situations like this, we're working with single families. We are kind of limited by what experience and knowledge we have, we have to reach out to each other, to try to figure it out.” They reported feeling inadequate when attempting to help immigrant families with children with DD since many of them do not have a lot of exposure with this population. They reported having to seek assistance from other colleagues and supervisors who may have some knowledge of the services available to this population.

### **Cultural Barrier**

Culture has also been an emerging theme affecting access to services. The cultural beliefs within immigrant families remain strong and at times put their culture or what others may think before accessing services for their children. In central Valley the largest immigrant population is Hispanic. A child welfare worker stated, “and you know within the Hispanic culture it's very rare for them to go out and seek help.” It is not uncommon within the Hispanic community to not seek help. This can be because of pride or the cultural stigma surrounding public assistance. A CVRC worker stated ...” they don't want to ask for help.” In some cultures, DD is a taboo topic, and most families don't talk about it. A CVRC worker stated,

There are folks that come from a different country, and they're pretty much set in their ways with certain things and it's hard for them to, you know, change their belief or mind on how a child can be more independent... this is a place where one can progress and

become more independent.. and it's best to kind of get it out there and, as... you know in our culture it's more of a stigma that you know we don't want other people to know that we have you know, have a child that has these kind of needs and so I try to put it in perspective for parents, you know, to understand like. God forbid anything happens to the parents... so we got to prepare that child the best to their ability.

Culture has made it difficult for parents to seek services because of their beliefs. In the Hispanic culture mothers tend to nurture and shelter their child and not give them independence. However, it is important to understand that just because someone has a disability does not mean they are not capable of accomplishing their goal. Another CVRC worker stated,

you know a lot of these cultures, you know do certain remedies for children with disabilities and you know, within the child welfare system we sometimes see that as abuse or neglect when it's really not you know it's just you know it's a cultural aspect that they heal these children or remedies that they learned throughout you know their lifespans that possibly help or not and stuff.

Participants shared that in some cultures, the disability can be cured with certain remedies. Therefore, families shy away from services because they believe their child will be cured. In some instances, families believe their child will grow out of it or go away on its own. All together from a child welfare perspective this becomes an issue because as a child welfare worker stated, “it can be seen as seen as abuse or neglect.”

### **Resource Deficiency**

Participants expressed that there is a form of resource deficiency specifically targeting immigrant parents with children with DD. They encounter many forms of barriers attempting to



access services in terms of resources. This includes financial barriers, services, transportation, and housing.

**Financial:** Immigrant families are typically working families. Most of them are farmworkers who work Monday through Saturday early in the morning and get off late. They are required to work long hours to provide for their families. Immigrant families with children with DDs have more expenses. This can include special foods, equipment, transportation, etc. It is extremely difficult for them to take time off due to their financial hardship. A child welfare worker stated,

“a lot of these folks don't have a 9 to 5 job in an office a lot of it is Agriculture, especially here in the valley, so a lot of people are like if I don't come to work, I'm going to get fired and I can't afford to get fired because I need to pay rent and buy food.”

Because immigrant families have to work every day to make ends meet, they sometimes miss their child's meeting or appointment. A CVRC worker stated, “I don't like it when they do have to take that time off because at that point they are not employed at places where they are going to get that time paid.” The worker expressed that they understand why some parents are unable to attend appointments. The worker comprehends how difficult it can be since they are losing out on money when they leave work. Another CVRC worker stated, “it's a money issue... because things are so expensive.” Due to their low paying job the money they earn is important and can be extremely difficult for them to stretch.

**Services:** Despite the many services out there for immigrant families to utilize, many are still out of reach. A child welfare worker stated,

“being told, no or denied our access to services because they don't have room... families are in need of services and because there is a waitlist the children may not be able to

access those services right away... you wait and wait sometimes will take a long time, and those you know those resources were definitely needed”

Therefore, families are struggling to receive the services for their child due to the long waiting list. There are times the child is in dire need of services but is not able to obtain them. A CVRC worker stated, “we do have more vendors, we do have more services, of course, but for my families that live in rural areas it's still difficult to find services.” Immigrant families tend to live in rural areas due to work making it difficult for them to receive services and having to drive out of town for them. Some families are wanting to service like respite care but are unable to because they are undocumented. A CVRC worker stated, “Again, a lot of them don't get the services because they don't have a social security number and that's where we have to hire somebody within the family or even hire someone to go into their home.”

Immigrant families are not able to hire their family members for respite care because they are undocumented and don't feel comfortable letting someone from the agency care for their child. This leads them to not utilize the service available to them.

**Transportation:** Transportation was a major barrier that was common amongst participants. There are many services available to immigrant families that are dispersed throughout the Central Valley. However, due to transportation, immigrant families have a difficult time getting to their child's appointments. A CVRC worker stated, “they weren't able to go, because you know they didn't have dependable transportation.” Transportation has been a huge barrier for families to take their children to adequate treatment or services. Some families can ask friends and family for a ride, but sometimes things come up and cancel and therefore are not able to make these appointments. A child welfare worker stated:

‘... A lot of children with disabilities tend to have to go to Valley Children's to seek treatment... our families are out in the rural areas... women don't know how to drive so they rely a lot on their husband, but their husbands are at work, a lot of time they miss these appointments... because of the lack of transportation.

Many of the services that are available to families are far from their homes. Families are obligated to do their best to attend these appointments but are struggling because they do not drive. Immigrant families are financially challenged and are sometimes forced to pay out of pocket for transportation. A child welfare worker stated, “Families would say we pay like 100 bucks to get transported to Valley Children's and that's a big burden on a family.

**Housing:** Housing was another major barrier immigrant families with children with DDs dealt with. Due to the financial burden their option on housing is limited. A child welfare worker reported, “Financial housing is like the main concern and the main issue that that I’m always dealing with” This worker stressed how in every investigation housing was always a concern. A CVRC worker stated, “housing is so high, right now, a lot of them are farm laborers.” Since these families are farmworkers, they are already struggling to make ends meet and as time progresses housing is getting more expensive. Most families are having to live within families in small spaces. A child welfare worker stated, “immigrant families... live in multiple families so some of our disabled children. Need space and there's a lot of equipment and then there's a lot of things that are expensive, so you have a big household... It can become a burden. “

It can be difficult for families to access affordable housing that has adequate space for their children. Especially when it comes to a child with DDs adequate space is necessary for their development.

## **Discussion**

Five themes emerged from this study. Language barrier, fear of deportation, lack of education or understanding of services, cultural barrier, resource deficiency that were followed by sub-theme including: financial barrier, services, transportation, and housing. The connection of these themes to past literature is discussed below.

In this study, language barrier was found to be the underlying issue preventing families from seeking services or being able to advocate for their children. Participants and a past study shared that information was not delivered and was misinterpreted due to language barriers (Khanlou et al., 2014).. Participants concluded families were not able to access services in their preferred language; consistent with the past studies (Arfa et al., 2020; Brassart et al, 2016; Cortez, 2020; Cummings & Hardin, 2017; Dijkstra & Rommes, 2021; Durà-Vilà & Hondes, 2009; Khanlou et al., 2014; Kim & Kim, 2017; Lim et al., 2020; Lindsay et al 2012; Lindsay et al, 2014).

Participants expressed fear of deportation is the primary reason families are reluctant to seek services. A study by Vargas & Pirog (2016) found that program use is linked to fear of deportation. Our research revealed that immigrant families with children with DDs live in multifamily and do not seek services to jeopardize those living in the home.. There is a dire need for research for those who intersect both systems of being an immigrant with DDs. Our study revealed children with a double status are incapable of receiving proper care, such as in-home supportive services and respite care because they do not have a social security. Our findings indicated that immigrant families take extreme measures like getting CPS involved to receive services for their children.

The findings revealed immigrant parents have a difficult time comprehending and understanding the literacy behind their child's diagnosis and what services are available to them.

This study found parents struggle with ABA because they don't know how to incorporate it into their everyday life because they do not understand it.. A Child Welfare worker stated it is challenging to refer families to services when the worker is not familiar with the population or services. Research by Afra et. al (2020) concluded that it is difficult for health professionals to refer families when they are not aware or educated on the services available to them.

Immigrant families with a different cultural background tend to believe remedies or cures will heal their child from the disability, aligned with what participants and previous research concluded (Durà-Vilà & Hondes, 2009). This study concluded families do not seek services because they don't want others to know they have a child with DDs: consistent with past research (Zechella, & Raval, 2015). Participants noted that immigrant families like to overly care for their children due to their culture. In correspondence, Pang et al., (2020) found that in some cultures families take on the role of a caretaker instead of helping them live independently.

This study confirms that immigrant families with children with DDs face a lot of basic needs challenges like financial barriers, access to services, transportation, and housing. Our results revealed immigrant families are deprived of services due to the long waiting period to access services. Additionally, immigrant families have low-paying jobs and need to work to provide for their families. It is difficult for them to access proper housing, transportation, and adequate resources (Cycyk, & Durán, 2020). Lastly, the findings in this study indicated that immigrant parents do not have dependable transportation.

## **Implications**

Accessing services was a common theme throughout the in-depth interviews. Participants and this author recommends more outreach programs with an on one guide for immigrant

families with children with DDs. Typically, these families are low-income with little knowledge of the services available to their children. By having an outreach program, immigrant families will be educated on how to access these services. Translation services are highly needed for immigrant families or having a human services worker that speaks their language. It is recommended to have more training that involves children with DDs or a specialized unit. Due to the high caseload, child welfare workers struggle to find someone who has worked with this population. Lastly, Providing immigrant families with legal services for them and their children, many of the families were not seeking services due to their fear of deportation and lack of understanding of their rights..

### **Limitations**

This study was qualitative. The sample size involved twelve (12) participants; it is recommended that this study be done in a large sample size since this does not represent all mothers with children with DDs in the United States. Participants for this study were recruited from the Central Valley, ten being from Fresno County and two (2) from Tulare County. In addition, our research is solely based on human service workers and their experience which limits the real experiences lived through the family and the individual with DDs. Future research should consider looking at the families' perspective through their lens as well as the individual with DDs.

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