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Navigating IEP Meetings: Effective Approaches for Supporting Asian Families of Children With IDD in Special Education

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ABSTRACT

Family involvement is an essential component of the special education process for youth with intellectual and developmental disabilities (IDD). In addition to the legal requirement that parents should be equal partners in the decision-making of the student's IEP program (IDEA, 2004), a bulk of empirical research demonstrates the positive impact of parent involvement on student outcomes. However, many families face barriers to participation in the special education process. Culturally and linguistically diverse (CLD), including Asian families, especially face systemic barriers when accessing services for their children with disabilities. In order to better understand parents' perceptions of stress in relation to individualized education program (IEP) meetings, special education knowledge, and family-professional collaborations, individual interviews were conducted with eight Asian families of children with IDD. The input provided by Asian parents provides many critical implications for practice.

KEYWORDS Asian parents, children with IDD, parental stress, IEP meetings

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The Individuals with Disabilities Education Act (IDEA, 2004) emphasizes that parents should have an equal role in creating an individualized education program (IEP) for their children with disabilities. While parent involvement has a positive impact on student outcomes (Howard et al., 2019), many parents, especially those with children with intellectual and developmental disabilities (IDD), face challenges in accessing disability services and are not treated as equal partners by school professionals during the IEP

process (Rios et al., 2020; Mueller et al., 2009; Vora, 2016). They also encounter difficulties with accessible safeguards and logistical support, such as transportation to IEP meetings (Leiter & Krauss, 2004; Mandic et al., 2012).

Culturally and linguistically diverse (CLD) families of children with disabilities often experience passive roles in IEP meetings (Hughes et al., 2008; Salas, 2004). Asian families, in particular, express concerns about participating in special education services due to disability stigma (Choi & Ostendorf, 2015; Kayama & Haight, 2018), inadequate cultural competency among special education professionals (Ikezaki et al., 2014; Kayama & Haight, 2018), and language barriers (Choi & Ostendorf, 2015; Ikezaki et al., 2014; Yan et al., 2017). These factors are also likely to influence their acceptance of their children's disabilities and participation in special education services (Cooc, 2018, 2019; Ikezaki et al., 2014; Kayama, 2010). Moreover, special education professionals' lack of cultural responsiveness may also discourage Asian families from actively engaging in the IEP process (Ikezaki et al., 2014; Kayama & Haight, 2018). Language barriers often make Asian families hesitant to advocate for their children and more likely to simply follow professionals' advice without question (Choi & Ostendorf, 2015; Ikezaki et al., 2014). Although interpretation services are available, some families are dissatisfied with these services due to interpreters' limited special education knowledge and time constraints (Choi & Ostendorf, 2015).

More specifically, Asian families have expressed notable concerns about engaging in special education services, which becomes increasingly significant given the underrepresentation of Asian students in IDD programs. Factors such as cultural stigma associated with disabilities, exacerbated by specific Asian cultural norms and values (Choi & Ostendorf, 2015; Kayama & Haight, 2018), present unique challenges for these families. Unlike in some other cultural contexts, there is a prevalent fear among Asian families of being labeled or experiencing shame and self-blame in connection to their children's disabilities (Ikezaki et al., 2014). These emotional reactions can significantly impact their acceptance of their children's disabilities and, subsequently, their involvement in special education services. Additionally, the limited cultural competency observed among special education professionals (Choi & Ostendorf, 2015) often fails to address these unique cultural and emotional needs. This gap in cultural responsiveness is a critical area our study aims to highlight, emphasizing the need for tailored approaches in special education to support Asian families effectively. Our findings and recommendations aim to bridge this gap, ensuring the academic success and better integration of children with disabilities from Asian backgrounds in the special education system.

While existing research on this topic has not thoroughly addressed the experiences of Asian families of children with IDD, partly due to their underrepresentation in special education services (Cooc, 2018, 2019), and recent studies have not accounted for current immigration trends or the diverse population makeup either (Yan et al., 2017), this study aims to bridge the knowledge gap regarding the unique experiences of Asian families with children with IDD in the context of special education services. By accounting for current immigration trends and diverse population makeup, this study can help shed light on the various challenges and strengths that these families encounter in their pursuit of adequate support for their children. Recognizing the unique needs and barriers faced by Asian families with children with IDD not only enriches the literature on this subject but also provides valuable insights for pre-service special education teachers and practitioners working in the field. This study utilizes a qualitative research method. Specifically, semi-structured individual interviews were conducted to answer the following research questions: (a) How do

Asian families describe their IEP meeting process? (b) How do families describe their special education knowledge? and (c) How do families perceive their family-professional partnerships?

Method

Researcher Positionality

Previously, each author had experience working with children with disabilities. This experience served as a strength because they had prior experience working with parents of children with disabilities and understand some of the complexities of schools. Additionally, each of the authors have taught Asian students with IDD which was a strength to the study because they had prior experience with parents, including Asian parents of children with IDD. Another strength is that the second author is an Asian and native Mandarin Chinese speaker. The authors recognize their position of power as interpreters of participants' lived experiences and thereby use member checks to address such power differentials. To minimize biases, we kept detailed field notes throughout the research process and consulted with one another regularly to self-evaluate and question interpretations of data (Brantlinger et al., 2005).

This study included eight participants who were Asian parents of children aged 3-21 with IDD. Notably, IDD was defined as an intellectual functioning and adaptive behavior that originates before the age of 22 (American Association on Intellectual and Developmental Disabilities [AAIDD], 2023). These parents took part in IEP meetings within the last year. The researchers recruited participants through social media, word-of-mouth, emails, and collaborations with disability organizations. To understand the experiences of these Asian parents in the special education process, the researchers conducted semi-structured interviews in English. The interview questions were taken from a previous research study on culturally and linguistically diverse families and their experiences in the IEP process (Rios et al., 2020). For example, questions included: "How would you describe your relationship with the school?" "How would you describe your role during the IEP meeting?" and "How did you feel during the IEP meeting?" The interviews were conducted over the phone and lasted between 34 and 70 minutes. Researchers took notes during the interviews to capture important information and insights. Specifically, the researchers took descriptive field notes to capture the tone of the exchange between the researcher and participant, describe the experience of the researchers conducting the interview and record details about logistics of the interview (Emerson et al., 2011). Descriptive field notes were taken before, during, and after the interviews. Reflective field notes were also taken during and after the interview to provide reminders during data analysis and to document insights, questions, and initial themes (Emerson et al., 2011). The researchers then analyzed the interview transcripts, identifying patterns and themes. Reflective and descriptive field notes were referenced throughout the coding process to provide context and supplemental data for analysis of patterns and themes. They achieved a 98% agreement rate when comparing their coding and analysis.

To ensure the accuracy of their findings, they used triangulation and member checking. This involved comparing information from different sources (e.g., interviews, field notes) and asking participants to review summaries of their interviews to confirm the accuracy of the researchers' interpretations. Throughout the study, the researchers were aware of their own experiences and biases, having previously worked with children with disabilities and Asian parents. They took steps to minimize these biases by not comparing personal experiences with participants and focusing on the parents' perspectives during the interviews.

Findings, Key Takeaways, and Practical Recommendations

This study explored the following domains: (a) the stress experienced by parents before, during, and after IEP meetings, (b) their knowledge of special education, (c) their perceptions of the family-school relationship, and (d) factors that facilitate or hinder effective collaboration. In this section, the key findings were presented for each aforementioned domain and followed by key takeaways and practical recommendations for each domain.

Table 1. Key Takeaways and Recommendations for Domain A (Stress Levels at Different Stages of the IEP Process)

Key Takeaways
<ol style="list-style-type: none"> 1. Before the IEP meeting: Parents reported feeling stress due to strategizing and preparing for the meeting. 2. During the IEP meeting: Parents experienced stress and anxiety, often feeling outnumbered by school personnel or anxious about their suggestions being accepted. 3. After the IEP meeting: Parents reported feeling stressed, depressed, or relieved, depending on the outcome of the meeting.
Recommendations
<ol style="list-style-type: none"> 1. Schools should provide support and resources to help parents manage their stress throughout the IEP process, such as informational materials, pre-meeting consultations, and debriefing sessions. 2. Special education teachers should consider collaborating with rehabilitation counselors to provide training sessions, support groups, or workshops for families on stress management, coping strategies, and self-care practices. 3. The support groups could feature guest speakers, such as special education experts or rehabilitation counselors who can provide consultations, special education related information, disability related Acts and regulations, and information on various topics relevant to the IEP procedures.

Domain A: Stress Levels at Different Stages of IEP Process

One main finding was that the majority of participants ($n = 6$; 75%) reported being stressed before, during, and after IEP meetings. Parents reported stress before the meeting, which mainly came from strategizing and deciding what services to ask for. During the meeting, stress and anxiety arose primarily from being outnumbered by school personnel and worrying about their responses. For example, Alice reported that while she feels stress prior to her son's IEP, that stress level rises during the meeting. Alice further stated, "My stress level always goes up [during the IEP] because I'm again trying to press the county office of education as well as the district representative, program specialists about what we can do, what they can do for me and my son." After the meeting, parents reported feeling stressed, depressed, or relieved, depending on the outcomes and expectations. For example, Manasa, reported feeling stress after her daughter's IEP meeting. Manasa further stated, "I was struggling with a stomach infection because I had so much stress

after the IEP meeting.” Notably, one participant, Gina, reported feeling depressed after her son’s IEP meeting because she felt like her IEP team did not agree nor acknowledge the input Gina reported regarding her son’s progress during the meeting. Gina further stated, “I felt depressed. It’s like an exercise in futility. It’s, you know, nothing I can do...almost like nothing I do will get us [IEP team] anywhere. That’s very frustrating.” As suggested by previous research (e.g., Rios et al., 2020; Jegatheesan, 2009), accessing school services is stressful for CLD families. Given the lack of research on Asian families' perception of the IEP process, this finding is alarming. This study also is consistent with previous research that the IEP process is likely to cause parental stress among CLD families (Rios et al., 2020).

Interventions should be developed to target stress before, during, and after the IEP meetings. Particularly, special education teachers could consider collaborating with rehabilitation counselors to offer support group services for Asian families of children with IDD. These support groups could provide an open and a safe space where those families can share with each other their experiences, challenges, and successes while navigating the IEP process and advocating for their children's unique needs. Moreover, Asian families of children with IDD can also benefit from the knowledge shared by peers in the support group. Those families will be able to receive emotional support and encouragement from their peers through such support groups, helping to alleviate feelings of isolation and stress and promote positive emotions. See Table 1 for key takeaways and recommendations for findings in domain A.

Domain B: Parent Knowledge of Special Education

The finding in domain B was that all participants reported having little to some knowledge of special education, with all participants expressing a desire to increase their knowledge; particularly, limited access to resources and support hindered learning in this area. For example, Emily stated that:

I would say I'm at 30% [with my knowledge of special education] because the last IEP after we [husband and I] met with the school, we [husband and I] also continued the meeting with our case manager.... just listed a few more resources that we [husband and I] can use. I'm still learning every day what's out there for him that can help him [son].

Regardless of the levels of knowledge of special education described by parents, all participants reported strong needs in support resources for learning about special education. For example, Kim stated:

I'm still learning [about special education]. I think it's a lot. Special education, there's a lot. I think as a parent, I have to educate myself first, what can the school provide, and what my child needs because every child is different. We have to know our child inside out and what he needs to help him [son] to succeed in the school environment and whether the school is able to do that...I want to continue learning.

Other participants also expressed their needs in learning about special education but had a lack of resources or access. For example, April stated:

We got a training through the mind clinic about the whole IEP process too, as well, from IPU [local PTI center] and from the mind clinic. Just having that information and just understanding a bit more about that process helps us be a bit more confident. It's funny how the school doesn't offer that type of education to the parents...we need more of those trainings and resources.

Prior research about CLD families of children with IDD documents the systemic barriers they face in accessing special education knowledge (Geenen et al., 2003; Kim & Morningstar, 2005). Asian families continue to face inequity in accessing such information (Chu, 2014). According to Boyd and Correa (2005), minority families lack knowledge about special education systems, which may limit their abilities to advocate for their children and connect with school professionals. This study contributes to our current understanding of the inequities and barriers Asian families face in special education. Consistent with previous research on CLD families of children with disabilities, parents are eager to learn more about the special education process that is culturally responsive (i.e., information provided to parents in their primary language; Rios et al., 2020; Rios et al., 2021). Notably, cultural values play a pivotal role in shaping perceptions of Asian families, especially when it comes to disabilities. As highlighted in the literature, there exists a significant stigma associated with disabilities with certain Asian cultures; and thus, overcoming the differences in cultural values regarding the stigma of disability is equally important. See Table 2 for key takeaways and recommendations for findings in domain B.

Table 2. Key Takeaways and Recommendations for Domain B (Parent Knowledge of Special Education)

Key Takeaways
<ol style="list-style-type: none"> 1. Some parents reported having little knowledge of special education and felt overwhelmed by the IEP process. 2. Other parents had some knowledge of special education, often due to personal or professional experiences. 3. Parents reported being eager to learn more about the special education process that is culturally responsive and embed cultural values.
Recommendations
<ol style="list-style-type: none"> 1. Schools should offer workshops or training sessions for parents to enhance their understanding of special education, the IEP process, and available resources. 2. Parents are encouraged to seek information from local Parent Training and Information Centers (PTIs). 3. School educators and professionals should undergo training that emphasizes and understanding of the cultural values prevalent in the communities we serve. This training can help foster empathy and awareness, contributing to more culturally responsive interactions.

Domain C: Family-School Relationship Building

The finding in domain C showed that the participants' perceptions of family-school relationships ranged from positive to negative and neutral. For example, Alice stated that “I think the relationship is good. On the whole, I trust the IEP team, and I think that they are trying their best to come up with solutions given the system is very limited in a lot of ways.” Emily also stated a similar experience and stated, “I think our relationship with the school is great. We [husband and I] love the school. We [husband and I] love the people that's helping Matt.” While Emily in general

perceived the family-professional partnership in a grateful manner, she also expressed her discomfort about the school’s transparency. For example, Emily stated that:

In the beginning, I was so grateful. So grateful to the whole team that was there. I was shocked to see so many people working for one child. The next moment, I was so upset. It was terrible that he lied to take away my son’s privilege.

Gina also shared her similar experience to this case by stating that “...not in agreement over the supports that are being given; ... I've played by their [school personnel’s] rules; ...it's just been so difficult because for every time I mention a concern.” While participants held either positive or negative perceptions about their relationships with the school and IEP team, some participants perceived this relationship in a neutral manner. For example, Amith stated that “I kind of have to play the game. You should be nice to the principal. You try to volunteer when you can in the classroom, even though if you don't agree with certain things, you don't necessarily blow up.”

Table 3. Key Takeaways and Recommendations for Domain C (Perceptions of Family-School Relationships)

Key Takeaways
<ol style="list-style-type: none"> 1. Some parents had positive relationships with the school and IEP team, trusting their intentions and efforts. 2. Others had negative or neutral relationships, feeling frustrated by the lack of transparency or feeling the need to maintain a respectful relationship despite disagreements.
Recommendations
<ol style="list-style-type: none"> 1. Open communication: Providing regular updates on the child's progress, offering opportunities for parents to voice out their concerns, and actively seeking parental input. 2. Trust-building: Building trust through active listening and genuine concern. 3. Increasing transparency: Providing clear and accessible information about the IEP process, proactively sharing updates on the child's progress, and involving parents in decision-making. 4. Addressing concerns in a timely manner: Address parental concerns by investigating issues, communicating steps taken, and collaborating to find solutions.

A family-school relationship refers to the collaborative and supportive partnership between families of students with disabilities and school personnel responsible for their academic and developmental progress. This relationship is characterized by open communication, mutual respect, and shared decision-making to ensure the optimal educational experience and outcomes for students with disabilities (Turnbull et al., 2009). Positive relationships were built on trust and mutual support, while negative relationships often involved a lack of transparency and agreement. Neutral relationships were described as respectful but marked by disagreements. Schools may

consider working on building positive relationships with Asian parents of children with IDD by focusing on open communication, building trust, increasing transparency, and addressing concerns in a timely fashion. See Table 3 for key takeaways and recommendations for findings in domain C.

Domain D: Barriers to and Facilitators for Family-School Partnerships

In terms of factors that facilitate or hinder effective collaboration, all participants reported both barriers to and facilitators for family-school partnerships. Barriers to effective collaboration included language barriers, both in terms of English proficiency and technical jargon, as well as poor experiences with the school system. For example, Aaron stated that "... if we see that he's having trouble with his finger and stuff, writing, and their lingo that's like, ...Oh, the fine motor...; we don't know those things; you have to be careful because sometimes we're talking about...we're using the wrong terminology..." Manasa also stated that "How do you challenge all those [school personnel] people? When I go to the meeting and literally a room full of a specialist. I have a language barrier. English is my second language." Such a language barrier did make it difficult for these families being difficult to express their opinions and self-advocate effectively. In addition to the language barrier, it was also frequently reported among participants that having a poor experience with the school system was also perceived as a critical barrier to the effective collaboration between families and school personnel. For example, Alice stated that:

I think it's the program specialists that keep their cards very close to their chest.

They have the district representative, and they do not always, ...I don't think that they always operate with the child's best interests at heart...

Facilitators for positive family-school partnerships included feeling heard and having school personnel understand the family's situation and needs. For example, April stated that "We [husband and I] were able to share our concerns. They're [school personnel] able to work with us [husband and I] in finding a goal or making new goals or making those changes. Just being heard and them [school personnel] being flexible is helpful." Aaron also stated that "They [school personnel] listen. I know they [school personnel] have their limits of what they can do and cannot do...but being heard helps."

Participants reported language and poor experiences with school personnel as being barriers to a positive family-school partnership (Chu, 2014). Advocacy is often a reactive (versus preemptive) action, as parents began to advocate for their children when they experienced a negative relationship with the school. Therefore, one way to address negative experiences with school personnel is to build a family-school working alliance among CLD, including Asian families of children with IDD (Rios et al., 2020; Burke et al., 2019). Thus, school personnel may consider ways to foster positive family-school partnerships. See Table 4 for key takeaways and recommendations for findings in domain D.

Limitations

Although a jumping point to examining Asian families' experiences in the IEP meeting, this study had a few limitations. First, we conducted one interview with each parent. Because perspectives may change over time (Cheatham & Ostrosky, 2009), multiple interviews may have provided richer data about parent's experiences throughout the IEP process. Second, the findings may have limited transferability given that the participants were only from one state (i.e., California).

Participants in other states may have different experiences in the IEP meeting process given the variability in state special education regulations. For example, in California, IEPs were not required to be translated into different Asian languages (i.e., Korean; Hmong). However, in other states and districts, IEPs are required to be translated in the caregiver’s native language. Third, there was heterogeneity in the sample. Specifically, there were participants from the Philippines and China. There may be intra-cultural differences in the findings depending on the country of origin. The findings from this study may not be transferable to such states. Fourth, this study did not collect information on the immigration status (i.e., first-generation vs. second-generation) of the participants. This limitation may impact the findings as experiences and approaches in navigating IEP meetings can vary significantly between different generations of immigrants.

Table 4. Key Takeaways and Recommendations for Domain C (Barriers to and Facilitators for Family-School Partnerships)

Key Takeaways
<ol style="list-style-type: none"> 1. Language barriers, including both English proficiency and technical terminology, made it difficult for parents to express their opinions and advocate for their children effectively. 2. Poor experiences with the school system, such as perceived lack of concern for the child's best interests, hindered collaboration. 3. Successful collaborations occurred when parents felt heard and school personnel were understanding of the family's situation and efforts.
Recommendations
<ol style="list-style-type: none"> 1. Schools should offer interpreters or translated materials for non-English-speaking parents and avoid using technical jargon during meetings. 2. Building trust and ensuring open communication can lead to more successful collaborations between parents and school personnel.

Conclusion

In conclusion, IDEA (2004) underscores the vital roles of parents, advocating for their active involvement in the creation of IEPs for children with disabilities. However, challenges persist, particularly for Asian parents of children with IDD, who often encounter barriers to accessing services and face inequalities in the IEP process. This is evident in the literature citing issues of inadequate cultural competency, language barriers, and a lack of cultural responsiveness among special education professionals, impacting the participation of CLD families, including Asian families. Despite existing research limitations regarding the experiences of Asian families of children with IDD, this study aims to address the knowledge gap by considering current immigration trends and diverse population makeup. By doing so, it strives to illuminate the barriers and facilitators unique to Asian families as they navigate the special education process. These insights not only contribute to the existing literature but also serve as a valuable resource for pre-

service special education teachers and practitioners, fostering a more inclusive and culturally responsive approach in the field.

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