

**Exploring Structural Barriers and Promoting Factors of Culturally and Linguistically Diverse Families in the Transition Planning through Community-Based Participatory Research**

Report Submitted by Catalina Tang Yan, PhD, Boston University School of Social Work

Written in partnership with the co-researchers of the Community Advisory Team (CAT):  
Angélica Bachour, Karen Zelaya, and Kathy Tsang

Mentor: Dr. Linda Sprague Martinez, PhD, Boston University School of Social Work

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## Abstract

Culturally and Linguistically Diverse (CLD) families and caregivers of youth with intellectual and developmental disabilities and co-occurring mental health (IDD-MH) conditions experience cultural, linguistic, and structural barriers during the transition-planning process. As a result, CLD youth and young adults with IDD-MH have poor outcomes in achieving post-secondary education, vocational training, competitive employment, and independent living. Limited research has partnered with CLD families to examine multilevel factors that promote and hinder CLD families' participation in the transition process. This study used a Community-Based Participatory Research (CBPR) approach to explore CLD families' perceived barriers and supports during the transition process at all levels of the socioecological model. Three waves of online multilingual focus groups with CLD caregivers of youth with IDD-MH (n=14) were conducted and analyzed using thematic analysis and concept mapping. Findings indicate that CLD families are supportive of their youth's aspirations. Community-based organizations and parent support networks were reported as relevant culturally and linguistically competent promoting factors to successful transition planning. Conversely, systemic barriers such as immigration and Social Security Administration's policies as well as limited access to interpretation services and translated resources were reported as major barriers for CLD families in the transition planning process. Findings suggest professionals and institutions serving CLD families of youth with IDD-MH need to integrate an intersectional and language justice lens to their interventions and programs.

**Keywords:** Culturally and Linguistically Diverse families, intellectual and developmental disabilities, language access, transition planning.

## Introduction

Successful transition planning after high school is one of the most important factors associated with positive competitive employment outcomes for youth and young adults with intellectual and developmental disabilities and co-occurring mental health conditions (Y and YA with IDD-MH). Essential components of effective transition planning outlined in the section of the Individualized Education Program (IEP) include parent and peers' connections, information and resource sharing, skill development, work experience, community engagement, and goal-setting (Christle & Yell, 2010). Effective transition planning is fundamental to secure post-secondary education, vocational training, employment, and independent living (Wehman, 2011). However, caregivers and Y and YA with IDD-MH experience numerous barriers (Hirano et al., 2018; Turnbull et al., 2006), in particular, Culturally and Linguistically Diverse (CLD) families whose preferred languages are not English and are not of European descent such as refugee and immigrant families (Wolfe & Durán, 2013).

CLD students classified as English Learners (EL) are one of the fastest growing populations with more than 50% growth over the past decade (Genesee et al., 2005). In 2013, over 61 million people born in the U.S. and overseas reported their home languages other than English (Zong & Batalova, 2015). According to the U.S. Census, about 41 percent (25.1 million) of people speak English less than very well and of those, close to 19 percent (4.7 million) were born in the U.S. to immigrant parents (Zong & Batalova, 2015). Caregiver involvement and participation in special education, particularly in the development of IEP is associated with increased positive post-secondary education and employment outcomes for youth with IDD-MH (Morningstar et al., 2010). However, CLD families experience compounding challenges at the intersection of language, culture, race, ethnicity, education, socioeconomic and immigration status (Reynolds et al., 2015; Wilt & Morningstar, 2018).

Research suggests major barriers hindering CLD families' participation in the IEP and transition planning process including negative professional attitudes blaming caregivers, discrimination toward CLD caregivers, stigma of special education, lack of information and knowledge, as well as contextual and structural barriers such as poverty, single parenthood, transportation difficulties, and lack of childcare (Kim & Morningstar, 2005). These barriers are reflected in racial disparities and disproportionate low rates of Y and YA with IDD-MH of postsecondary education attainment, competitive employment, and independent living. For instance, Employment rates continue to be lower for African American (42%) and Hispanic youth (36%) with disabilities when compared to their White counterparts (62%) (Cameto et al., 2003). Moreover, White youth with disabilities are more likely to earn higher wages and have higher rates of enrollment in postsecondary education programs than African American and Hispanic youth with disabilities (Cameto et al., 2003).

One of the most prevalent barriers CLD families experience in participating fully in their children's special education is having access to linguistically and culturally responsive services. While schools are legally mandated to provide transition plans to students' IEP and ensure caregivers can participate fully in their preferred language throughout all communication, planning, decision-making under the Disabilities Education Improvement Act (IDEIA, 2004), findings of a scoping review suggest culturally and linguistically competent services in schools are inconsistent and lacking (Wilt & Morningstar, 2018). For instance, CLD families have described delayed translated IEP relevant transition documents, discrimination, and poor communication with school staff and teachers due to language and cultural barriers (Geenen et

al., 2001; Ju et al., 2018; Povenmire-Kirk et al., 2010). Additionally, research suggests school personnel are more likely to draft transition components of the students' IEP focusing on vocational careers with limited family input and as a result, excluding key components to CLD families such as financial aid (Trainor et al., 2019). These issues are at the intersection of immigration, language, and disability, which generate compounding disadvantages for CLD families such as burden of care, stigma, service utilization, and adequate supports (Alsharaydeh et al., 2019). Effective transition planning necessitates families to dedicate substantial time to participate in transition-related activities and CLD families struggle to negotiate competing priorities, demands of family, and employment, which may generate emotional toll and increased levels of stress (Scott, 2010).

### **CLD Families Participation in the Transition Planning Process**

Research suggests engaged caregivers with advanced knowledge on the transition process and who are actively communicating with transition professionals taking on multiple roles including advocate and teacher, can better navigate the disability service system and support effective transition planning (Canha et al., 2013; Lee & Burke, 2020). However, CLD families experience a wide range of challenges in the transition planning. While CLD families have been perceived as passive actors and less involved in schools, research has documented compounding barriers CLD families experience in their efforts to fully participate in their children's special education (Kim & Morningstar, 2005). For instance, research indicates CLD families struggle with multilevel and systemic barriers to transition planning including racism, inaccessible translated materials, poor interpretation services, and difficulty navigating education and adult service systems that are not culturally or linguistically responsive (Hirano et al., 2018). Despite these barriers, there is evidence that CLD families care deeply about their children's education and transition to adulthood by advocating for effective transition planning services, communicating with school personnel, documenting communication, engaging in legislative advocacy, and seeking for resources to increase their knowledge in the transition planning process (Burke et al., 2019; Burke, Rios, et al., 2020; Burke, Rossetti, et al., 2020; Hwang et al., 2020). Although CLD families actively seek educational resources to navigate these multiple service systems, CLD families struggle to find culturally responsive and translated resources in their preferred language which leads to having limited knowledge about the legal requirements for transition and not having supports to address conflicting cultural attitudes with school personnel (Wilt & Morningstar, 2018).

While there is evidence that interventions to promote self-determination in students with disabilities are associated with effective transition planning and achievement of postsecondary and employment goals (Shogren et al., 2012, 2018), findings of a meta-analysis study suggest these interventions have yet to be inclusive of students with diverse backgrounds as nearly half of participants in the interventions identified were White and less than half assessed family members and additional key stakeholders' perceptions (Burke et al., 2020). Moreover, while research has evaluated outcomes of multi-family group psychoeducation programs and trainings for families and Y and YA with IDD-MH, most of the participants in these studies have been primarily White, English speakers, and highly educated (DaWalt et al., 2021; DaWalt et al., 2018; Taylor et al., 2017). Addressing the particular needs of CLD families is essential and reconceptualization of special education teacher preparation to redefine family engagement and partnership is key (Brown et al., 2019; Miller, 2019). Additionally, reviews of scholarly literature indicate the need for an increased attention to the development of culturally and linguistically

responsive IEPs in collaboration with CLD families, youth, and young adults (Tran et al., 2018). To improve the outcomes for CLD families of Y and YA with IDD-MH in transition-planning, postsecondary education, and employment, it is critical for all stakeholders supporting this population to understand these multilevel barriers and implement culturally and linguistically diverse practices to promote collaboration, trust, and self-determination with CLD families (Cote et al., 2012; Cycyk & Durán, 2020; Rodriguez et al., 2014).

### **Community-Based Participatory Research (CBPR)**

CBPR is an approach to knowledge production rooted in participatory inquiry and action that seeks to partner with community stakeholders as co-researchers throughout all phases of the research process and translate research to advance equity (Wallerstein et al., 2017). CBPR methodologies present numerous benefits such as skill development between researchers and stakeholders with disabilities and development of inclusive and collaborative partnerships in translational science, particularly with individuals with IDD-MH (Schwartz et al., 2019; Schwartz et al., 2020). Additionally, CBPR is characterized by key principles of sharing power equitably with community stakeholders throughout all decision-making processes, achieving a balance between research and action mutually beneficial to all partners, and promoting co-learning and skill building within the partnership (Wallerstein et al., 2017) These guiding principles can potentially engage meaningfully CLD families of children with IDD-MH to co-create equitable academic and community research partnerships and contribute to the development of culturally and linguistically responsive interventions that can meet the needs of CLD caregivers of Y and YA with IDD-MH in education and healthcare settings (Kwon et al., 2018; Suarez-Balcazar et al., 2018).

While research has implemented CBPR approaches to examine nuanced understandings regarding the lived experiences of CLD caregivers of Y and YA with IDD-MH, most of the literature has focused primarily on examining issues of stigma (Ellen Selman et al., 2018), impact evaluation of specific disability-related training (Hayward et al., 2021), health-promoting lifestyles (Suarez-Balcazar et al., 2018), and asset mapping (Suarez-Balcazar et al., 2021). Limited research has yet to partnered with CLD caregivers fo Y and YA with IDD-MH to examine multilevel barriers related to transition planning.

### **Current Study**

There is extensive research documenting family involvement as a fundamental factor leading to effective transition and employment outcomes. However, findings of a scoping review of the literature indicate that there is limited studies exploring evidence-based strategies to engage meaningfully families, particularly CLD families in the transition-planning process (Kramer et al., 2018). Research has not yet explored multilevel factors that promote or hinder transition process outcomes through a participatory, culturally, and linguistically responsive approach. Understanding the experiences of CLD families in the transition planning process has the potential to inform interventions that support CLD caregivers navigate the transition planning process and increase the likelihood of positive employment and postsecondary aspirations and outcomes for Y and YA with IDD-MH.

This study sought to investigate the following research questions: 1) What are some relevant qualities, skills, and knowledge CLD families have regarding the transition planning process?, and 2) What factors promote and hinder CLD families in the transition planning process at each level of the socioecological model? We examined these research questions

through three waves of online multilingual focus groups framed as a family institute that sought to explore the research aims in addition to share relevant educational and community-based resources with CLD families.

### **Community Action Team**

Drawing CBPR approaches to research, a Community Action Team (CAT) was formed and served as the primary research team to co-lead with the university affiliated researcher in all phases of the research project. In the Fall of 2020 and Spring of 2021, the university researcher worked in collaboration with two immigrant caregivers of Y and YA with IDD-MH to identify areas of inquiry and co-draft the request for proposal.

Upon successfully securing funds for the proposed project, the immigrant caregivers of Y and YA with IDD-MH recruited additional caregivers to join the CAT. The university affiliated researcher has prior experience working with the grassroots coalition members of the CAT for the past couple of years in CBPR projects that explored CLD families' cultural and linguistic barriers in healthcare and educational settings that have been awarded (BUSSW, 2021). The CAT was established with three CLD caregivers who brought valuable lived experiences as parent advocates.

Drawing from CBPR principles of equitable power sharing and cyclical skill building processes, CAT members identified and agreed upon group agreements, communication, roles, decision-making processes, and online team meeting schedules and agendas to collectively manage allocation of project funds, design research protocols, collect and analyze data, and disseminate research findings. Modified consensus was used to prioritize the leadership and decision-making of CLD caregivers of Y and YA with IDD-MH. CAT members were involved in all decision-making processes and in the event CAT members disagreed with one another, ample time was allocated to discuss differences while prioritizing CLD caregivers' experiences and reach full consensus. CAT members received a stipend for their participation throughout the project. Remaining funds were allocated for family institute participants, language workers, and research assistants supporting with research-related tasks. The university affiliated researcher served as a facilitator during CAT meetings and shared relevant information, resources, events, and announcements from the funding institution with the CAT.

## **Methods**

### **Study Design**

Multilingual Community-Based Participatory Research (CBPR) approaches and qualitative research methods were employed to examine the main research questions of the study. Qualitative methods were identified as appropriate to investigate through an exploratory lens the meaning making processes of phenomena (Maxwell, 2012), in this case, the multilevel factors that promote or hinder CLD families' experiences in the transition planning process. The research team employed focus groups to generate a collective body of shared knowledge, beliefs, and opinions of CLD families' experiences. Focus groups can elicit in-depth stories and perspectives of vulnerable populations and provide opportunities for participants to discuss shared and different opinions on a particular subject (Adler et al., 2019). Focus groups were appropriate to capitalize CLD caregivers' group experiences and stimulate discussion to better understand barriers and supports experienced in the transition planning process. Three waves of online focus groups (3hrs/each) were conducted in zoom to explore more in detail the main inquiry areas.

## **Participants**

All focus group participants (n=14) identified as immigrant mothers, speakers of the top three non-English languages spoken in Massachusetts: Spanish (n=6), Portuguese (n=3), and Cantonese (n=5). Mothers reported countries of origin included: Brazil (n=3), China (n=5), El Salvador (n=2), Honduras (n=3), and Guatemala (n=1). Mothers' years living in the U.S. ranged between four to twenty six years with an average of nineteen years. Additionally, mothers indicated being unemployed (n=2), unable to work (n=2), self-employed (n=3), working part-time (n=4), and full time (n=3). All mothers indicated Limited English Proficiency and indicated having children with IDD-MH conditions including: learning disability, developmental and mental delay, G11 syndrome, epilepsy, autism spectrum disorder (ASD), VACTERL association, Attention Deficit Hyperactivity Disorder (ADHD), anxiety, and cerebral palsy. Mothers' children's ages ranged between fourteen to twenty years old with an average of eighteen years old. Most mothers reported having MassHealth insurance (n=12) and a couple of mothers reported having private health insurance. Half of the mothers (50%) reported having a total household income less than \$25,000 (n=7). A quarter of mothers (25%) reported having a total household income between \$25,000 and \$34,999 and another quarter (25%) reported between \$35,000-\$49,999.

## **Procedures and Ethics**

Upon the approval of the University Institutional Review Board, the research team used purposive sampling, a nonprobability sampling technique to recruit focus group participants (Etikan & Bala, 2017). Multilingual recruitment materials were shared with local community-based groups such as parent support groups serving CLD caregivers of youth with IDD-MH. Research team members conducted individual phone interview screenings with interested participants in their preferred languages indicated initially. In the event participants were not available to participate in phone interviews, online multilingual demographic surveys were distributed for participants to fill out. After carefully reviewing the intake notes and engaging in group discussions, the research team selected participants who met the following criteria: 1) participants with English proficiency and whose preferred language was from the top three languages spoken in Massachusetts (i.e. Spanish, Portuguese, and Chinese), 2) participants with Y and YA with IDD-MH conditions in the transition-planning process, and 3) participants with availability and capacity to commit fully to attend all three waves of online focus groups via zoom. The research team contacted selected participants to share invitation to focus group sessions framed as a series of online multilingual family institute sessions.

Research team members conducted and facilitated three waves of multilingual online focus groups via zoom with all participants (n=14). Each focus group session had a duration of three hours and each participant received a \$275 gift card at the end of the all three sessions for their participation. Language workers (i.e. interpreters and translators) attended all focus group sessions to provide simultaneous language interpretation in three languages (i.e. Spanish, Portuguese, and Chinese) via zoom. University affiliated researcher led an orientation to all language workers (n=6) and provided additional training on facilitation to all CAT members in addition to technical support.

At the start of each focus group session, the university affiliated researcher obtained verbal consent to record and participate from participants in their preferred languages via zoom. Study's activities, expected time of involvement, voluntary participation, confidentiality of the

data, benefits, and potential risks were reviewed. Participants also had the opportunity to ask any questions and leave sessions at any time. Upon successfully obtaining verbal consent from all participants, CAT members introduced group guidelines and agreements such as honoring confidentiality, being mindful of providing ample opportunities for everyone to participate, and respect each other's unique experiences and views. CAT members led introductory exercises for participants to get to know each other. Then, participants were asked questions regarding their experiences in the transition planning process. Small breakout group and large group discussion formats were used. Drawing from CBPR principle to promote skill development and knowledge building, at the end of the first two focus group waves, the research team invited representatives from community-based organizations to share briefly relevant resources and supports for participants in the transition-planning process. In addition to facilitating focus group sessions, research team members took notes and engaged in debrief sessions at the end of each focus group session.

### **Data Analysis**

The research team analyzed the data using Interpretative Phenomenological Analysis (IPA) which emphasizes lived experiences and interpretation of meaning making in relation to a specific phenomenon within a social context (Miller et al., 2018; Smith & Osborn, 2015). We used IPA to explore CLD caregivers' meaning making processes related to their lived experiences in the transition planning process through five major steps. First, the research team conducted multiple readings of the focus group transcripts to familiarize themselves with the data (Smith et al., 2009). Then, each research team member analyzed the language and content by annotating descriptive comments on the side of the transcripts separately (Smith et al., 2009). The research team focused on examining closely similarities and differences across participants' experiences. Then, the research team met to discuss emerging themes and meaning-making patterns across the annotations made in each transcript, particularly on transition planning. Lastly, a collective analysis of the different relationships across emerging themes identified across multiple cases using concept maps (Castleberry & Nolen, 2018), namely a visual exercise that consists of using diagrams and arrows to depict different relationships (Smith et al., 2009).

### **Findings**

Mothers discussed in-depth their experiences and perceptions of promoting and hindering factors in the transition-planning process. While mothers' cultures and languages varied, there were overlapping experiences and understandings shared across groups. Three major themes emerged: 1) mothers' unwavering commitment to learn, collaborate, and support, 2) peers and community-based groups as essential culturally and linguistically responsive sources of supports, and 3) social security, immigration and healthcare exclusionary policies as institutional barriers. These themes depict key factors that promote and hinder effective transition-planning at each level of the socioecological model (i.e. individual, interpersonal, and institutional) (Bronfenbrenner, 2005).

#### **Mothers' Unwavering Commitment to Learn, Collaborate, and Support**

All mothers expressed a steadfast commitment to support their children's post-secondary aspirations and dreams. This was reflected in the words of Luz, a mother from El Salvador.

When asked what motivated her to join the focus group sessions framed as a multilingual online family institute, Luz stated:

Aprender más sobre cómo ayudar a mi hijo en la transición a la etapa de ser adulto... Me gustaría conocer unos recursos para ayudar más a mi hijo. Quiero conocer algunos más testimonios de otras personas que también están pasando por el mismo proceso y poder ayudarnos.

To learn more about how I can support my son in the transition process to adulthood... I'd like to learn about resources to better support my son. I'd like to learn about the testimonies of other people who are also going through the same process to better support each other.

Similarly, Francisca, a mother from Brazil explained: “Porque quero entender os direitos e benefícios que meu filho pode ter [Because I want to understand the rights and benefits my child may have].” Mothers expressed shared feelings of deep care and commitment to support their children’s transition to achieve their aspirations after high school. Juliana stated: “Quero muito ajudar meu filho a realizar seu sonhos ; gostaria de entender e receber um suporte pois preocupado muito com futuro deles [I really want to help my son make his dreams come true; I would like to understand and receive support because I care a lot about their future].” Chu shared similar sentiments when describing her main motivations to join the focus group sessions:

因为我大儿子已经 20 岁，二儿子已经 17 岁，我很想了解多些 22 岁之后由学校过渡到社会的各种安排，想他们有一个好的过渡令之后的生活，工作，社交等等有一个更好的安排。也可以将我所知道的跟其他有需要的家长分享和倡议。

Because my eldest son is 20 years old and my second son is 17 years old, I would like to know more about the various arrangements for transitioning from school to society after the age of 22. I want them to have a good life, work, and social life after the transition process. I can also share and advocate what I know with other parents in need.

In general, mothers were eager to learn about the transition planning process and also expressed deep care to support their children’s postsecondary aspirations. Mothers were also driven by a collective commitment to support and exchange resources with each other.

### **Peers and Community-based Groups as Essential Culturally and Linguistically Responsive Sources of Supports**

Mothers unanimously identified limited access to culturally and linguistically relevant resources to transition-planning as a major barrier. However, interpersonal support networks and community-based groups were characterized as the main sources of information, resources, and support. Mothers reported parent support groups (14) followed by Community-Based Organizations (7), friends (5), and family members (2) as main sources of support and information related to transition-planning. Among some of the community-based groups and organizations mothers identified included the Federation for Children with Special Needs (FCSN), Boston Children’s Hospital support groups, Boston Chinatown Neighborhood Center (BCNC), and Massachusetts Advocates for Children (MAC). Additionally, government

institutions mentioned included Massachusetts Rehabilitation Commission (MRC) and the Department of Developmental Services (DDS).

Even when culturally and linguistically accessible resources and supports related to transition-planning were provided by their peers, community-based organizations, and government institutions, the frequency in which these materials were offered varied. For instance, although mothers described receiving resources in their preferred languages, when asked how often they have been able to find the resources in their preferred language of communication, only two out of the fourteen mothers indicated “often”. Near half of the mothers reported “sometimes” and half of the mothers indicated “sometimes” and “rarely”.

Access to valuable information and resources in caregivers’ preferred languages is key to inform the ways caregivers can advocate and ensure transition-planning components are integrated appropriately in the student’s IEP. This was evident in Adriana’s experience after attending a community workshop where she learned about her rights as a parent to request additional time to better understand all components of the IEP rather than accepting the IEP without fully knowing what it entails, in particular, how it can potentially support the transition planning of the young adult. Adriana explains:

O curso foi muito importante pra mim, pois me alertou pra várias questões que eu não tinha conhecimento. Por esse motivo pedi até o adiamento da reunião de IEP pra que eu tenha tempo de me preparar melhor e finalizar o curso.

The course was very important for me, as it alerted me to several issues that I was not aware of. For this reason, I even asked for the postponement of the IEP meeting so that I have time to better prepare and finish the course.

In summary, mothers discussed the important role of parent support groups, peers, and community-based groups in disseminating culturally and linguistically relevant resources regarding the transition-planning process. While mothers indicated having access to translated materials to their preferred languages, the frequency in which these materials were accessible varied. Mothers’ increase in knowledge about the transition-planning process through these community-based groups can be key in securing successful implementation of transition-related goals of the IEP.

### **Systemic Barriers: Social Security, Immigration, and Healthcare Policies**

While mothers described community-based institutions and peer networks as valuable sources of support and information, mothers also characterized specific institutional policies across the fields of immigration, healthcare, and social security as factors that can hinder parent training and access to financial support. For instance, when mothers were asked whether they have heard previously of public assistance programs such as Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI), half of the mothers reported having prior knowledge of these programs. When facilitators asked mothers what specifically they knew about these public assistance programs all mothers answered not having a lot of information or understanding about the details of these programs except one mother who defined SSI as “an amount of money given for having a disability”. Additionally, when asked for specific recommendations for the Social Security Administration to better support CLD caregivers of Y and YA with IDD-MH conditions, mothers unanimously highlighted the importance of ensuring

institutions such as SSA to offer services that are culturally and linguistically accessible. This was evident in Ana's recommendation. She stated:

Crear más espacios donde las personas puedan aprender y entender mejor todos estos procesos y recursos. Padres como nosotros pasamos tantas dificultades y retos día a día, que es de mucha ayuda que nos llegue la información en nuestro idioma.

To create more spaces where people can learn and better understand all these processes and resources. Parents like us experience so many difficulties and challenges every day and it's very helpful that the information we get is in our language.

In addition to translated written materials and additional workshop opportunities to better understand the services and resources, mothers also recommended to have digital translated resources, particularly SSA's website. Susan stated:

多办一些其他语种的 workshop, 多一些其他语种单张和小册子, 网站上可以转换成其他语种, 令其他语种的有需要人士明白和找寻到需要关心, 了解, 申请的途径。

More workshops in other languages, more brochures and pamphlets in other languages, and the website can be converted into other languages, so that people in need who speak other languages can understand and find ways to care, understand, and apply.

Besides translated resources and materials, mothers also suggested to have access to interpreters as well as bilingual or multilingual staff. Clara suggested: "Pienso que es muy bueno que tengan personal que hablen de todos los idiomas para los padres puedan informarse mejor [I think it's really good that they have staff who can speak all the languages so parents can be better informed]."

While mothers described various community-based resources and workshops in their preferred languages, mothers indicated the content of these workshops varied and that often times did not include or consider immigrants' lived experiences and barriers including undocumented and mixed immigration status. This was reflected in the CAT members' experience inviting guest speakers to present relevant resources on transition-related subjects. Local advocates, attorneys, researchers, nonprofit community leaders, and a parent with a young adult with IDD-MH were eager to present on topics such as transition-planning goals in the IEP, supportive decision-making, and alternative guardianship. However, when CAT members reached out via email to the local SSA representative to present more in detail about SSA disability and eligibility, the representative replied: "... I cannot speak much to the immigrant piece unless they are a refugee or the adult of a minor is a legal citizen... Also, I cannot address resources for the immigrant population as my focus is strictly on SSA disability."

Although some institutions focused on specific services for specific target populations, mothers reported anti-immigration exclusionary policies as a major factor that hindered mothers' capacity to access financial support and advocate for the successful implementation of transition-planning processes. When mothers were asked to map promoting and hindering factors at each level of the socioecological model, the majority of the mothers described "políticas migratorias" [immigration policies], "No tener licencia" [Not having a driver's license], "Temor de ser

deportados” [Fear of being deported], “Políticas de inclusao” [Inclusion policies], and “Apoyos económicos para pagar abogados y evaluaciones independientes” [Financial support to afford independent evaluations and legal support]. Additional barriers identified included “受到某些醫療機構限制” [Medical institutions’ restrictions], and “在公立醫院較能接收需要的醫療服務” [Better access to needed medical services in public hospitals].

These barriers exacerbated further mothers’ concerns and limited knowledge of regarding the transition-planning process. Even with valuable supports and resources found at the community level, mothers expressed feeling fearful, insecure, and worried about their children’s postsecondary outcomes, aspirations, and future. When asked about what comes come to mind when hearing the word transition-planning, Francisca stated:

Medo, em relacao a condicao financeira, e como dar suporte aos sonhos dele sabendo e como dar suporte sabendo da realidade. Inseguranca, pois ele ainda é muito dependente, e o futuro, em deixar ele sozinho.

Fear, in relation to the financial condition, and how to support his dreams knowing and how to support him knowing the reality. Insecurity, as he is still very dependent, and the future, on leaving him alone.

Similarly, Luz described: “Preocupada sobre ¿Qué va pasar después? ¿será que nuestros hijos podrán tener oportunidades?” [Worried about what’s going to happen after? Would it be possible for our children to have opportunities?]. Chu also agreed:

擔心過期的問題，学业跟不上、面對社會、就算畢業可能無法達到工作要求、孩子的行為（情緒化、一會兒開心過會又不開心）、孩子的時間管理和計劃能力。

Worried about overdue issues, not keeping up with school, facing society, may not be able to meet job requirements even after graduation, child’s behavior (emotional, happy and unhappy for a while), child’s time management and planning ability

However, mothers described being persistent in continuing their advocacy and ongoing support to their children’s transition planning process. Luz stated:

Es algo que tal vez para nosotros no es fácil pero tampoco no nos damos por vencidas. Seguimos tratando, porque nosotros con el poco conocimiento que tenemos a veces las ayudas no han sido suficientes. Entonces hemos tenido que recurrir para tratar de como nosotros mismos podemos ayudar a nuestros hijos.

This is something that it’s not easy for us but we don’t give up. We keep trying, because with the limited knowledge we have, sometimes the supports haven’t been enough. We’ve had to figure out how we can support our children by ourselves.

In summary, mothers identified key factors at the institutional level that can limit access to cultural and linguistic supports for an effective transition-planning process. Mothers described various strategies to promote language access, namely access to translated written and digital materials, educational workshops in mothers’ preferred languages, language workers,

interpreters, and bilingual or multilingual staff. Without these strategies, mothers described having very little knowledge about public programs such as SSDI and SSI. While specific institutions target specific populations, mothers underscored the importance of considering the immigrant experience, in particular, systemic barriers including immigration policies that limit mothers' access to financial supports and programs.

## **Discussion**

This study sought to illuminate what factors promote and/or hinder the transition process of CLD families of youth and young adults with IDD-MH conditions. Additionally, this study also sought to identify CLD families-generated recommendations and develop multilingual educational and employment intervention curricula. Understanding how to better support CLD families in transition planning early on using culturally and linguistically competent strategies can potentially improve employment outcomes given the key role families play in supporting youth and young adults with IDD-MH conditions. Consistent with previous research, findings of this study highlighted the role of multilevel factors at the individual, interpersonal, and institutional level that promote and hinder the transition-planning process, particularly for CLD families of Y and YA with IDD-MH.

Language access plays an essential role in family engagement, knowledge building, and change in practices to better support effective transition planning processes. Despite the fact that institutions that receive federal funds are legally mandated to provide language access services for constituents to fully participate (Executive Order No.13166, 2000), mothers recommended institutions such as SSA to have written and digital translated materials in addition to interpreters and educational workshops in their preferred languages. This is consistent with existing literature that suggests culturally and linguistically competent services in institutions such as schools are inconsistent and lacking (Wilt & Morningstar, 2018). Mothers identified peer networks such as parent support groups and community-based groups as key sources of having relevant materials in their languages.

Findings of this study illustrate preliminary evidence on barriers and supports CLD families experience in the transition planning process and how social institutions including schools, healthcare providers, community-based organizations, and employers can better support CLD families of youth and young adults with IDD-MH conditions in the transition to post-secondary education and employment (Hirano et al., 2018). Consequently, findings of this study can inform the development of culturally and linguistically competent educational employment interventions across school-based and community-based transition programs, employment agencies, and vocational rehabilitation. For instance, to dismantle deficit-based perceptions of CLD families of Y and YA with IDD-MH, research suggests stakeholders to build collaborative and reciprocal relationships with families that honor families' strengths and engage meaningfully throughout key decision-making processes in the assessment, planning, and articulation of the goals and vision for their youth (Curtiss et al., 2019; Rao et al., 2020). Supporting transition planning and early employment can potentially reduce reliance on SSI and SSDI over an individual's lifetime.

## **Limitations and Future Research**

This study included a small sample size of CLD caregivers. While mothers who participated spoke languages of the top three non-English language groups in Massachusetts, the

number of mothers is not representative of all CLD mothers of Y and YA with IDD-MH conditions. Thus, the findings may have limited transferability and is not generalizable to all CLD caregivers from different language groups and geographic locations. Additionally, all participants identified as mothers and the experiences of caregivers who identify with other gender identities, sexual orientation, and relationships (e.g. guardians, foster parents, etc.) with Y and YA with IDD-MH may not be reflected in this study. While this study examined the collective experiences of mothers across three time points through the use of focus groups, findings illustrate themes captured within a specific time point. Future studies should explore additional perspectives from additional types of cultural and linguistic groups of CLD caregivers with different positionalities. Moreover, longitudinal studies should explore the perceptions of multiple stakeholders including caregivers, school staff, and adult service personnel regarding the ways CLD caregivers' experiences shift over time using mixed research methods, particularly throughout the different phases of youth's transition to adulthood. Further, examining multilevel factors relevant to the immigrant experience such as the role of undocumented and mixed immigration status can shed light on how institutional policies can potentially support or restrain access to transition-related resources. Despite these limitations, findings contribute to existing scholarship to better understand CLD caregivers' experiences and multilevel factors at the intersection of language and culture that support and hinder the transition-planning process.

### **Implications for Social Security Administration**

To reduce reliance on public assistance programs such as Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) and increase competitive employment opportunities, it is essential to gain a deeper understanding of multilevel factors that promote and hinder the transition process of CLD families. Findings of this study highlighted the role of peers, parent support groups, and community-based organizations in providing culturally and linguistically accessible resources, materials, and supports to promote effective transition-planning for Y and YA with IDD-MH conditions. Research suggests multiple key stakeholders in the transition planning process including parents, classroom teachers, school administrators, adult service providers, and state policymakers indicate the lack of reliable and consistent implementation of core tenets of the IEP process as a major issue (Snell-Rood et al., 2020). Examples include inappropriate goal-setting, failure to provide appropriate skill-building and community relationships, lack of effective communication and involvement of all decision-makers throughout the planning process, and insufficient accountability of adult service providers which can hinder the ability of Y and YA with IDD-MH conditions to secure and maintain employment opportunities (Snell-Rood et al., 2020). This was evident in the various multilevel factors that mothers identified and discussed in-depth throughout the focus group sessions, particularly anti-immigration exclusionary policies and restrictive healthcare access. Consistent with previous research, this study suggests involving various stakeholders including CLD families, parent support groups, and community-based groups in the planning and implementation of multilevel, culturally and linguistically responsive interventions to improve transition outcomes. For instance, the Social Security Administration could strengthen partnerships and collaborations with community-based organizations to enhance culturally and linguistically responsive dissemination of SSA programs that consider the multilevel factors that CLD immigrant caregivers of Y and YA with IDD-MH identified. Such strategies may not directly affect Social Security Administration practices and policies, but early intervention

strategies to support CLD immigrant caregivers and their youth and young adults in the transition process may contribute to positive postsecondary education and workforce readiness outcomes while reducing or delaying the need for reliance on Social Security benefits. Findings of this study reinforced the importance of developing interventions that integrate a lens that transcends language access to ensure culturally and linguistically responsive approaches to parent education and family engagement value CLD caregivers' cultural perspectives and take place in CLD caregivers' preferred languages consistently. Rather than focusing on individual-based interventions and deficiencies of CLD families, studies suggests that research, practice, and policy should consider a greater emphasis on changes at the institutional level such as schools and adult service systems (Hirano et al., 2018).

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