

Reaching out to culturally and linguistically diverse families: strategies and challenges reported by parent training and information center staff

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Abstract

Within special education policy and practice, parents are expected to advocate for their children to receive appropriate special education and related services. However, the majority of parents report feeling disempowered to advocate; families from culturally and linguistically diverse (CLD) backgrounds may feel especially disempowered. Federally funded Parent Training and Information Centers (PTIs) exist in each state to empower historically underserved (including CLD) parents of children with disabilities. In this study, we examined how PTIs educate and empower CLD families through semi-structured interviews with 13 PTI staff members who work with CLD families across five states. The participants emphasized the importance of strategies such as conducting outreach in local communities and developing parent leaders among the CLD families they support. The findings also indicated that PTIs struggle with addressing external, systemic barriers which influence CLD families. Implications for research, policy, and practice are discussed.

Keywords: Culturally and linguistically diverse families, advocacy, Parent Training and Information Center, special education

Reaching out to Culturally and Linguistically Diverse Families: Strategies and Challenges

Reported by Parent Training and Information Center Staff

The Individuals with Disabilities Education Act (IDEA) expects parents to advocate for their children with disabilities to receive special education and related services (Kalyanpur, Harry, & Skrtic, 2000). However, although 70% of parents report needing advocacy to ensure that their children with disabilities receive appropriate services, the majority of parents report not knowing their special education rights and feeling disempowered to advocate (Public Agenda, 2002). Parent advocacy is needed to improve service delivery and reduce non-compliance with IDEA because 28 out of 50 states did not meet IDEA Part B requirements according to analysis of State Performance Plans and Annual Performance Reports (U.S. Department of Education, 2017). Additionally, children from culturally and linguistically diverse (CLD) backgrounds are especially more likely to require parent advocacy as CLD, versus White, European American children with disabilities are more likely to experience suspensions (Krezmien, Leone, & Achilles, 2006), have lower employment and graduation rates (Taylor-Ritzler et al., 2010), be segregated from their peers (Losen & Orfield, 2002), and receive fewer services (Magaña, 2013).

The terminology of CLD typically refers broadly to individuals whose primary language is not English and/or who are not European American (Wolfe & Duran, 2013). Such a broad designation inherently applies to individuals who differ along other characteristics and experiences. For example, refugee and immigrant families typically face additional barriers to school engagement and advocacy (e.g., trauma, cultural adjustment) compared to CLD families born in the United States (McBrien, 2005; Pine & Drachman, 2005). It is critical to consider the intersections of the multiple characteristics and experiences each CLD family may experience,

including socioeconomic status (SES), class, race, ethnicity, geographic setting, and disability. CLD families often have multiple minoritizing identities with respect to race, class, disability and other characteristics (Erevelles & Minear, 2010). Because a single characteristic cannot explain all life experiences (Pastrana, 2004), intersectionality is an attempt to examine how multiple forms of oppression and other social processes affect CLD individuals. For some families, disability may be a primary identity with race and class being additional characteristics (Erevelles, 2002). Our use of CLD throughout this paper reflects an intersectional approach.

In alignment with the expectation for parent advocacy, since the 1970s, Congress has funded over 70 Parent Training and Information Centers (PTIs) to educate and empower parents to advocate for their children with disabilities. Indeed, with respect to advocacy, PTIs are critical stakeholders as this is their primary objective. In 2012-2013, PTIs reported serving 665,529 families of children with disabilities: 27% of these families were from CLD backgrounds (National Parent Technical Assistance Center, 2012). By federal mandate, the majority of staff must be family members of individuals with disabilities and should reflect the population of families they serve. Notably, the primary purpose of PTIs is to empower historically underserved parents of children with disabilities (National Parent Technical Assistance Center, 2012), including CLD parents given that they may feel especially disempowered to advocate (Hughes et al., 2002; Shapiro et al., 2004). In two longitudinal studies of nationally representative samples of students with disabilities, CLD parents and parents of low SES, compared to White, European American parents and parents of higher SES, reported lower rates of participation and satisfaction with their involvement in IEP and transition meetings (Wagner, Newman, Cameto, Javitz, & Valdes, 2012). Thus, although CLD children are at greater risk for not receiving services and needing parent advocacy, CLD parents may feel especially disempowered (Irvin et

al., 2012; Magaña et al., 2013; Wolfe & Duran, 2013). Given the history of PTIs in serving CLD families, PTIs may have important strategies to educate and empower CLD families of children with disabilities.

Although special education advocacy training is a growing field (Burke, 2013), there are few documented strategies to educate and empower CLD families of children with disabilities. For example, many states have Parent to Parent programs wherein a trained parent of a child with a disability is matched with another parent of a child with a disability. By matching two parents of children with disabilities, the parents have a shared commonality (i.e., having a child with a disability) enabling them to build trust and rapport with one another. Notably, however, the majority of participants in Parent to Parent programs are White and European and American (Robbins et al., 2008). Other strategies may extend to outreach efforts. For example, families from the mainstream culture may be easily identified using parent supports groups (Solomon, Pistrang, & Barker, 2001). However, CLD families may respond to other forms of outreach (e.g., personalized attention, Magaña, 2000). Thus, to educate and empower CLD families, PTIs may use unique recruitment strategies to develop trust with CLD families.

In addition to identifying strategies to educate and empower CLD families, it is also important to identify barriers to educating and empowering CLD families so interventions can be developed to remove or overcome such barriers. Previous research has documented the systemic barriers CLD families face in accessing services (Harry, 2008). Among CLD families, systemic barriers to advocacy include: lack of knowledge (Leiter & Krauss, 2004); caution about sharing information (Cartledge et al., 2002); and feelings of intimidation (Fish, 2008). Although CLD families are overrepresented in special education (Albrecht et al., 2011), their voices are the least likely to be heard by professionals (Leiter & Krauss, 2004). Notably, many barriers may be

systemic and relate to the school; such barriers may include relegating CLD families to listening, passive roles (Williams, 2007) and lacking cultural awareness (Shapiro et al., 2004; Hughes et al., 2002). Unfortunately, most research about CLD families tends to be deficit-based (Harry, 2002) and based on small, convenience samples (Burke, 2012). By understanding the perspectives of PTIs about barriers, we may have a more holistic understanding of barriers that need to be addressed.

In special education, cultural differences are largely ignored (Burke, 2012). Of the limited extant research, studies often combine minority families into the category *culturally and linguistically diverse* (Harry, 2002). However, cultural values may impact parent advocacy. For example, Latino, versus White, European American, mothers of children with IDD report significantly greater positive parenting impact (Blacher et al., 2013). Such positive parenting may relate to *confidente* support, wherein individuals belong to an ethnic support network (Zuniga, 1992). Like Latino families, African American families also reap benefits (e.g., a greater sense of purpose) from having a child with IDD (Blacher & Baker, 2007) perhaps due to greater religiousness (Rogers-Dulan & Blacher, 1995). In addition to strengths, Latino and African American families may face similar barriers including discrimination and SES (Magaña & Smith, 2006). By examining how PTIs differentiate their advocacy strategies to educate and empower cultural groups with shared commonalities, this study helps identify culturally responsive strategies.

Given that students with disabilities are increasingly diverse (Albrecht, Skiba, Losen, Chung, & Middleberg, 2011) and parent advocacy is especially needed for CLD families (Shapiro, 2011), it is necessary to identify strategies to educate and empower CLD families. By their mission, PTI staff members work daily to educate and empower CLD families, thus they

are perfectly situated for inclusion in this study. Because there is very little extant research in this area, we designed an exploratory, qualitative study to examine PTI staff members' perceptions of working to educate and empower CLD families. The perceptions of PTI staff members extend the literature by offering insight about strategies and barriers to working with CLD families. We addressed three research questions:

1. How do PTI staff educate and empower CLD families of children with disabilities to advocate for their children?
2. What barriers do PTI staff face in educating and empowering CLD families?
3. How do PTI staff address the complexities of educating and empowering CLD families?

Method

A qualitative research design matched the exploratory goal of the study. We were interested in examining how PTI staff members perceived their work in educating and empowering CLD families of children with disabilities. The participants were viewed as the experts, and understanding their perspectives and descriptions of their experiences was central to answering the research questions (Bogdan & Biklen, 2003).

Participants

Participants included 13 adults (12 females, 1 male) who worked at PTIs with CLD families of children with disabilities. Inclusionary criteria for participants included: being over 18 years of age, being employed at a PTI, and working specifically with CLD families of children with disabilities. Participants worked in PTIs from five states: Illinois ($n=5$), Massachusetts ($n=3$), New Jersey ($n=3$), Rhode Island ($n=1$), and Tennessee ($n=1$). Illinois has two PTIs (and participants worked at both) while the other four states each have one PTI. The participants' roles were primarily as a specialist working directly with CLD families ($n=9$) or as

an administrator overseeing the specialists ($n=4$). Titles for the specialists included Parent Training and Information Specialist, Bilingual Parent Training and Information Specialist, Family Outreach Coordinator, Family Resource Specialist, and Care and Technical Information Specialist. Titles for the administrators included Director, Assistant Director, and Advocacy Manager. All but one of the participants were parents of individuals with disabilities themselves; further, 10 participants reflected CLD backgrounds themselves. See Table 1 for further information about participants.

Recruitment

Reflective of the intersectional nature of the CLD label, we sought a varied group of participants who worked with CLD families (e.g., PTIs who worked with urban CLD families and PTIs who worked with rural CLD families). We recruited participants using multiple avenues. The first and second author relied on their relationships with PTIs to recruit participants from Illinois, Massachusetts, Rhode Island, and Tennessee. The authors e-mailed individuals at the PTIs in these states explaining the study and determining whether they were interested in participating. We also utilized snowball sampling at several of the PTIs, yielding multiple interviews at each PTI. Additionally, the first author also used a similar process to reach out to the PTI in New Jersey after a recommendation from one of the participants.

Procedures

To explore the perspectives of the participants, we conducted individual interviews. Specifically, data were collected from participants in two ways: (1) an information sheet and (2) a semi-structured interview protocol. The information sheet included demographic information (e.g., gender, age) as well as information about how many CLD families the participant has

served in the past month. Participants completed the information sheet before the interviews were conducted.

To develop the interview protocol, we completed a literature review about CLD families of children with disabilities and PTIs. With the initial interview protocol, we conducted a pilot and a cognitive interview with the director of a PTI that served primarily CLD families. Cognitive interviews help determine whether participants understand the questions (e.g., comprehension) and are able to answer the questions (e.g., retrieval, judgment and response) (Collins, 2003). Cognitive interviews are “think alouds” wherein the respondent is supposed to state (aloud) what they are thinking about the interview question, how they are interpreting the question, and questions they may have about the wording. From the pilot and the cognitive interview, we made minor changes to the protocol and the information sheet. For example, we added probes to elicit stories and descriptive examples about working with CLD families. Upon revision, each author’s University Institutional Review Board approved the protocol and study.

Upon indicating interest in participating in the study, the author scheduled an interview with each participant at the time and date preference of the participant. Interviews were conducted over the phone. Previous research has indicated that in-person and phone interviews likely yield the same results (Sturges & Hanrahan, 2004). Before beginning each interview, each author talked to the participant about recent happenings at the PTI and in working with CLD families. Each author then introduced him/herself, the purpose of the study, and his/her relation to advocacy. Specifically, each author was a family member of someone with a disability and had collaborated with PTIs on previous research. The second author had previously worked at a PTI. By sharing common interests and the relation to disability, the authors and the participants could develop rapport (O’Toole, 2013). We explained to participants at the start of each

interview that we utilized a broad definition of CLD meaning culturally and linguistically diverse families including families from different racial/ethnic backgrounds, low-income families, and undocumented families.

The first author conducted seven interviews; the second author conducted six interviews. Each interview lasted between 60 and 120 minutes. All questions on the interview protocol were asked of each participant (see Appendix 1). The authors took detailed field notes throughout each interview to note the key elements of participants' responses. In the last 10-20 minutes of each interview, the author summarized the main responses of the interview based upon his or her notes to present to the participant for feedback and clarification. Participant responses were accurately recorded; the changes consisted of corrections to names of community agencies and participants' training experiences. Each interview was audio-recorded and transcribed verbatim to be used as data. In addition, the authors wrote one-to-two-page researcher memos after the interview to highlight each participant's demographic information and the emergent themes in the interview. The authors communicated throughout data collection (e.g., weekly phone calls) to discuss whether they were reaching saturation by sharing the interview summaries and emergent themes with each other. In total, the authors collected 316 single-spaced pages of data consisting of interview transcriptions (258 pages), field notes and researcher memos (32 pages), and participant demographic forms (26 pages).

Data analysis

Data analysis was ongoing and inductive, and it aimed to capture the participants' perspectives on how they educate and empower CLD families of children with disabilities. We engaged in a two-stage process of open and then categorical coding (Creswell, 2013). First, we read each interview transcription two to three times to become familiar with them. Then, we

independently open coded four (30%) interview transcriptions by hand, marking data units with key words to highlight statements that were important or interesting related to our topic and the three research questions (Bogdan & Biklen, 2003). We shared and discussed these codes, resulting in a master list of over 100 codes. Through further discussion, we refined and categorized these codes until consensus to develop a codebook with 18 categorical codes. Examples of codes included *Conduct Outreach*, *Communication/Language*, *Develop Parent Leaders*, *Develop Trust*, *School Barrier*, *PTI Barrier*, and *Complicated/Complex Families*. The codebook included definitions of each code with examples and non-examples of each code that provided explicit guidelines for distinguishing between codes to ensure consistency of coding. We recoded the initial four interviews and then the remainder of interviews using the codebook. We discussed coding during weekly phone calls throughout this process to check for the possibility of additional codes or other changes; there were none. The first author coded with HyperRESEARCH (HR) 3.7.3 qualitative analysis software. Using HR allowed us to analyze code-specific reports of all coded data units to identify sub-codes within each category. For example, *Complicated/Complex Families* included sub-codes such as limited transportation, limited finances/resources, negative school experiences, perceptions of disability, cultural differences, and language barriers.

We identified themes through organization of the categorical codes and sub-codes by research question and discussion of the relationships among codes and categories. We also looked for patterns of difference with respect to geographic setting, level of education, SES, and other characteristics of CLD families served by the participants, as well as by the participants' race, ethnicity, and gender; we did not find any such patterns. Finally, we utilized negative case analysis to look for disconfirming evidence of themes and categories, and did not find any.

Quality indicators and credibility

Our methods adhered to quality indicators of an interview study, including purposefully identified participants, appropriate interview questions, and fair and confidential representation (Brantlinger, Jiminez, Klingner, Pugach, & Richardson, 2005). We also ensured credibility and trustworthiness through member checks, data triangulation, investigator triangulation, and peer debriefing (Brantlinger et al., 2005). Each author presented summaries of interview responses to participants at the end of interviews for first level member checks of accuracy of responses. We also engaged in second level member checks by reviewing interview summaries and thematic findings with all participants by email and asking them to note anything to change or add. We received no major changes. The authors engaged in data triangulation by checking the accuracy of interview summaries (field notes) when reading interview transcriptions, and checking for accuracy across the interview transcriptions and the participant demographic forms. Investigator triangulation included the close collaboration (e.g., weekly phone calls and multiple weekly emails) of the authors through all stages of the research process, especially while developing the interview protocol and analyzing the data. Peer debriefing occurred when an experienced qualitative researcher, who also studies family-school collaboration in special education, affirmed the study design and provided critical feedback on interpretation of the study's results while at a national conference with the authors. In particular, she emphasized the importance of understanding and presenting the unique examples within various cultures of how some of the common barriers and strategies manifested.

Findings

The findings are presented in direct response to the three research questions. First, there is a brief overview of how participants characterized PTI support for all families and then their

description of four specific strategies for educating and empowering CLD families. Second, the participants described three types of barriers to educating and empowering CLD families: school systemic barriers, PTI barriers, and competing and complex barriers of CLD families. Third, because of the competing barriers facing many CLD families, the participants described three additional strategies they employed during what they often described as a longer and more complex process of supporting them to develop advocacy skills for their children with disabilities. Unless otherwise noted, these strategies and barriers reported in the Findings were representative across all or nearly all participants.

Strategies to Educate and Empower CLD Families

Each participant described specific strategies to educate and empower CLD families within the same overall PTI goal for all families with whom they work. The participants described this overall goal as a mission to support families to educate themselves and advocate for their children rather than PTI staff doing so. Rebecca described this mission: “We’re the bridge, not the destination. We’re giving shoulder-to-shoulder peer support to help our families get to the next phase of their lives.” To empower all families, PTIs offered trainings, connected families to resources, facilitated support groups, described options and next steps to families, helped families prepare for IEP meetings, and attended IEP meetings with families until they could do so on their own. Specific strategies to support CLD families are described below.

Conduct intensive outreach in the community. Nearly all of the participants described an initial and ongoing strategy to engage in networking and cultivate a presence in the local communities of CLD families. By being in the community, participants expanded their knowledge of local services and supported greater numbers of CLD families. For example, Paula described, “We need to reach [leaders in the community] to be able to get to that population

because it's not reading flyers. It is the mouth-to-mouth experience." The participants made community connections through churches and mosques, raised awareness by attending community events (e.g., community fairs), advertised their services via community radio and television stations, and utilized social media to stay in touch and schedule support group meetings with families. Additionally, some of the participants strove to engage with CLD families in the community to become a familiar face to them, as well as to increase the convenience of meeting (e.g., so they did not have to miss work to come to the PTI). Finally, the participants proactively engaged in community outreach to better coordinate inter-agency service delivery. As an example, Thi described her approach: "I really try to outreach in particular areas. What agencies are out there? So, trying to really identify those assistance agencies that already have the relationship with the community and what can the [PTI] do to support them." The participants described sharing PTI flyers and brochures at other community agencies serving the same population, leaving their cards with social workers, and collaborating with local hospitals and pediatricians so that medical professionals would refer families to PTIs.

Maximize access to trainings and resources. All of the participants emphasized the importance of making every effort to ensure that CLD families could access PTI trainings and materials. For example, PTIs offered trainings in multiple languages and often had written materials translated in multiple languages. Melissa described the benefits of increasing linguistic access: "They [CLD families] are going to see they are coming to a Spanish training. They are going to see the community there. They are going to feel safe and trustworthy." Additionally, the participants described offering multiple formats for standard trainings, such as through developing webinars and by scheduling speakers during regularly scheduled support groups rather than as separate events.

Build trust with families. PTIs likely employ this approach with all of the families they support as trust is critical in supportive relationships. However, all of the participants stressed that building trust was especially important for CLD families and therefore something they purposefully and actively sought to achieve. Most participants explained they emphasized trust due to CLD families' lack of familiarity with PTIs and often a mistrust of professionals.

Reflective of a common approach, Alba described:

So, the first thing that I had to do, I need to build the relationship in order for me- no, in order for them to open up, and let me go through and start to talk with them about the child, about the disability, how can I help them, how can I bring the resources, [and] how can I support them at the school system.

Relationship building occurred through listening to CLD families and relied on identification of common experiences. Though it was included in the description of our sample, it was a critical finding that 10 of our participants represented diverse cultural and linguistic backgrounds, and 12 participants were parents of children with disabilities themselves. Thus, the participants experienced and overcame through advocacy many of the same challenges as the CLD families they supported. For example, Hector described common linguistic barriers:

I grew up as a child of an immigrant knowing the barriers of not having information provided in their language. I've seen the barriers that my parents went through just to get informed, so I lived it. So, I know what the parents are going through. I guess that's something that helps me help the families that I work with because I'm a product of a parent who was an immigrant and didn't understand anything, and basically I had to translate for them at times to get information to them. It's really personal for me because I lived it and it brings back memories of the horror stories that my parents went through.

Related to the common bond of being parents of children with disabilities, Kadejah's description serves as an exemplar across comments by all participants:

We are parents just like they are which is, I think, really one of the best things when parents talk with us here because they are not talking to someone who is just looking at information on a screen and saying, "Okay, I suppose I should tell you this." We are all parents of special needs kids.

In addition to sharing common experiences and backgrounds, the participants with the specialist roles described that their training prepared them to build trust with families. Prior to assuming their positions at the PTI, or during their first year, they attended a parent leadership training through the PTI (often yearlong with monthly sessions) that fostered knowledge and skills in special education policy and practice, advocacy, and parent support.

Cultivate parent leaders. Once participants had developed community connections and regular contact with families, over half of the participants described seeking to develop parent leaders. Participants sought parent leaders to both cultivate CLD families' advocacy skills and to assist PTIs in their efforts to reach and support CLD families. Rebecca described her focus in cultivating parent leaders' advocacy skills as modeling and teaching them to "tell their stories with a purpose." The participants hoped to further the skill development of parent leaders by putting CLD families in positions to share their stories and to teach others. Reflective of the time demands of PTI staff members, our participants described providing support to hundreds of CLD families. Thus, participants welcomed any assistance they could get, as San described:

If my time cannot help the parents for their IEP meeting, sometimes my parent leader will also help me and go with the parent for their IEP meeting. I really do think the parent leader will be another way to really help my community start to form the knowledge

about all the information about their child with disabilities because, as a parent leader, you have a child with disabilities and you can share your own experiences.

Barriers in Educating and Empowering CLD Families

School systemic barriers. All of the participants reported that school systemic barriers limited their ability to educate and empower CLD families. Specifically, participants reported that many schools lacked cultural awareness; accordingly, participants struggled to help CLD families develop strong partnerships with schools and to access needed services. At the most basic level, participants reported that language barriers continued to be a problem. Describing that many schools did not provide impartial and professional interpreters at IEP meetings, Thi reported, “The language barrier is always a challenge because they [the schools] are not enforced.” Thus, advocacy is critical. However, CLD parents struggled to advocate for interpreter services. Rebecca reported, “The other piece is something where we may consider it a simple request, which is just to be able to understand the information in our own language, and parents are sometimes fearful to request that and stop a meeting because of [needing the] services of an interpreter.”

Lack of cultural awareness, however, extended beyond language. Participants reported that schools did not often consider cultural differences. Describing the lack of cultural awareness, Zineb reported, “You have a school that is heavily populated with Latino kids...but Mexican and Puerto Rican is different. They [the schools] just put them in one packet, in one spot...so they really, really have to have cultural awareness.” Additionally, Zineb and others reported examples of Muslim students in transition programs where they had job placements in food services with pork and/or alcohol, which directly conflicted with their Islamic principles.

Other perceived systemic barriers included negative perceptions of CLD families. Specifically, because of the negative perceptions of CLD families, participants reported that schools sometimes engaged in discriminatory or punitive practices. Paula, who primarily educated and empowered Latino families, reported “Sometimes the school is, you know, discriminating to families—immigrants in general.” Similarly, Hector explained, “Parents are calling in and [they were] bullied in a situation that it could be from a very minor thing to a very severe thing, so it’s important that the parents know the procedures, and there’s no information out there for parents.” Participants described several examples of veiled verbal threats concerning immigration status and the withholding of information related to parent rights and possible services other than what the school proposed. Participants also described what they felt was a general sense of low expectations for CLD families held by school personnel. Melissa stated, “The school tries to put the blame off themselves. You know, they might put it back on the parent....parents do get beaten up.”

Finally, participants reported that many schools did not have culturally responsive strategies to develop partnerships with families; instead, participants reported that many schools reinforced the power differential between themselves and CLD families. Regarding the former, Alba described the lack of responsiveness of schools in working with CLD families. She stated,

I think a lot of times that there are cultural barriers...the point I'm trying to get to is culturally, they put a lot of faith and trust and they assume that the school and the staff is going to just handle things. And sometimes, unfortunately, that's not the case. Sometimes you find that there seems to be a pattern of certain family stereotypes that often have consistently been having issues, where clearly you start to wonder or be concerned or to

question whether the school staffing is taking advantage of the fact that these families do not speak English as their first language.

Regarding the latter (i.e., emphasizing the power differential between schools and parents), Peg reported, “Often, [the school] is kind of abusing power with them [families]”.

PTI barriers. All of the participants reported that the lack of capacity (i.e., time and people) and funding at the PTIs limited their ability to educate and empower CLD families. Regarding the lack of capacity, participants reported that they needed more personnel to support the growing population of CLD families of children with disabilities. Especially given that CLD families face greater systemic barriers in accessing services, participants reported that, without more staff, they were not able to meet the needs of CLD families including spending the time necessary to attend IEP meetings with families. Thi reported “I think in the future parent centers should concentrate on hiring more [staff] with diversity in terms of language speakers because there’s a lot people who need help and I know that it’s a barrier, at information centers everything has a cost, but I think that it’s imperative that part of their grant they should be put information out there that asks for more money like that because this country is really diverse.” Another related barrier was lack of time. Participants reported that many CLD families needed more time to share their stories and receive assistance. However, given the limited staff of PTIs, it was difficult to provide the needed time to educate and empower CLD families. For example, for CLD families with a language barrier, it was time-consuming to pursue translation and interpretive services. Paula reported, “It is time consuming...you know because one person cannot do it all. It is consuming....especially if you are going back and forth between English and Spanish—there are some days that I come home and I just have dead brain.”

Participants also mentioned another PTI barrier: lack of funding. Funding was perceived as a barrier as CLD families may need additional supports to attending trainings. For example, some CLD families may need stipends for transportation and childcare to attend trainings. Darlene reported that, due to the competing and complex barriers facing many CLD families, more supports need to be offered. She described receiving state funding to educate and empower African American families in an urban district; she reported, “I think that’s why we have been so successful with the RTI training and getting people there was the food that brought them in. And plus we offered a stipend, you know, they got \$20 stipends.”

Competing and complex barriers facing CLD families. Participants also reported that it was difficult to address all of the competing barriers facing CLD families. When initially reporting about barriers in educating and empowering CLD families, Zineb reported “So many layers, so many layers.” Thi similarly stated, “It’s really complicated, and we do it on a daily basis.” Barriers included lack of resources (e.g., finances and transportation) as well as greater challenges (e.g., stress, illiteracy, negative experiences with the schools). Regarding the former, participants reported that it was difficult to empower CLD families due to their lack of resources to be able to advocate. For example, Zineb reported, “Financial barriers. I can’t get to school. I can’t do an observation. I can’t access my child’s records because I don’t have a car.” Participants also reported other challenges afflicting CLD families. When describing her advocacy with Latino families, Paula reported about the negative relationships between many families and the school: “You find a lot of families of color: they still have a lot of resentment because of the barriers and the treatment. And the way they have been treated and everything. They have had bad experiences.” Further, some families struggled to comprehend special

education policy and to problem solve within the IEP process, as Peg described: “When the education level is very low, they have a harder time trying to understand what they need to do.”

Strategies Addressing the Complexities of Educating and Empowering CLD Families

Linking to the competing and complex barriers facing CLD families (reported above), each of the participants emphasized the intense challenge of educating and empowering CLD families. They described that CLD families often experienced multiple, competing or intersecting barriers that resulted in a longer and more complex process of supporting them to develop advocacy skills for their children with disabilities. This process included three broad strategies for addressing these complexities.

Meet other needs first. We already reported on the participants’ emphasis on the importance of building trust with CLD families. However, participants also consistently described that building trust takes time. Additionally, CLD families often experienced more immediate needs requiring attention from PTI staff prior to building trust and providing support for advocacy skills. Thi, while describing advice she would give to others working with CLD families, explained the importance of being patient and recognizing these other needs:

Many times, it's very frustrating as a professional to really give the family the resources, and then you make another call and nothing has ever been done. It's not like the family is not trying or think that your time is not important; sometimes for the parents to really break that initial barrier, it is a very difficult process. So, be patient with the families.

The participants described several additional layers of CLD families’ experiences that took priority during this support process. Several participants working with refugee families cited the need to address trauma-related emotional well-being and cultural shock at being in a new environment with a new language prior to focusing on their advocacy skills. Several

participants, as Zineb, also noted a longer process due to the effects of trauma in the lives of some African American families from large urban areas that they supported: “African American, low-income families have a lot of trauma in their life by guns and violence in the community. It took me three to four years for families to work with me. It was perseverance for those families.” Lastly, over half of the participants worked with families who were undocumented and emphasized the need to stress that undocumented families are still entitled to services. Such families were often fearful of not only advocating for their children, but also of engaging in the special education process, as Alba described:

Now, it is going to be worse because they don't want to open anything, because some of them they don't have immigration situation clear, and they were afraid. They thought they don't have any rights to ask for the services at school. Now, it is going to be worse.

They going to take anything the school wants to give you because they are afraid to claim their rights for their child. It's going to be worse for me.

Darlene, among other participants, hoped that PTIs could expand upon existing trainings to address citizenship issues and special education for this population.

Bridge cultural differences. All of the participants described various instances of problem solving and explaining cultural differences between CLD families and school personnel, suggesting that bridging cultural differences was central to their work. First, perceptions of disability varied across cultures. Participants supporting Latino families described that families tended to view disability as a taboo subject, while many Asian families of children with disabilities were stigmatized in their communities, as Manisha explained:

I am a South Asian. I come from central India, and in that community there is a stigma still, to be able to have a child, even my child, or anybody being labelled or identified

with any disability or any kind of diagnosis, would really be a stigma in the community.

It's a really big value of the parents. They really come in more or less a denial mode, and they can't really use the system of care, which is laid down beautifully to assist the children, so the denial initially is really, really a very big barrier that they don't utilize these services, and eventually it's the child who suffers in the end.

LaTonya also saw denial of disability diagnoses from other CLD families: "Because they are not ready to grasp the idea that their child has a disability. Because to them, that's like their child can't move on in life. I see that, 'My child is not like that!' or 'My child don't do that!'"

Some families misunderstood the nature of disabilities and their functional characteristics at a basic level, manifesting in resistance to diagnosis, treatment, and ultimately, advocacy. Thi described that some Vietnamese families believed that developmental disabilities, such as autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD) were not lifelong conditions and that doctors could fix or cure them in the short term. Kadejah, an immigrant from Trinidad, shared a similar misunderstanding in her own family: "When my son was first diagnosed, and my mom was still around, she would kind of make light of the diagnosis. She thought it was some passing style, and I kid you not, she said, like vegetarianism. He's not a vegetarian; it's autism!" San shared the gendered cultural belief held by some Chinese families that boys with ASD or ADHD were just active boys and would grow out of it: "He's just difficult. You don't need to worry about that." Such views were held by some of the families the participants supported, but also by their extended families (e.g., the grandparents of children with disabilities). Thus, PTI staff were often supporting CLD parents to advocate within their own families prior to advocating with school personnel.

The second type of cultural differences the participants addressed were those related to conflicting values and traditions held by families and school personnel. Over half of the participants described Arab, Asian, and Latino families who were collectivistic (versus individualistic) in their approaches to raising their children and planning for the future, which conflicted with schools emphasizing self-determination and independence during transition planning. Additionally, when families included extended relatives, such as grandparents, they were more likely to engage in the traditional cultural values. Other families struggled with cultural differences in gender roles related to how authority and agency played out during IEP meetings. Zineb described multiple examples of supporting Arab fathers to interact with school personnel who were mostly women: “I said I understand the Middle Eastern culture, and let me tell you something. You are in America. Women will look at you in the face. Women will be a little bit loud. Women will talk. That is no disrespect.” Another gender-related aspect was the lack of involvement in the IEP process by fathers. Hector, the lone father we interviewed, strove to support more fathers, specifically Latino fathers.

The third type of cultural differences related to CLD families’ understanding of schooling in the United States compared to their own schooling experiences in their home countries. Some families did not hold a conceptual understanding of special education because it did not exist or was not as extensively established by a federal law in their country. San described that Chinese families did not often understand special education, let alone the expectation of advocacy:

Sometimes new immigrants, we are so used to the educational system in our country, because in our country we don't have special education, we respect the teacher. ...In our country, the teacher is the one to decide, like how to teach your kids and what's the best for your kids, and you have no control about that. Just listen when teacher tells you have

to do this. Here, you have the special education, and the system is different, and we don't know how to play that role, and also sometimes, for our parents it's really a whole new ballgame and they never say they could talk to the school.

Similarly, Rebecca and Alba, described that Latino families sometimes struggled to understand special education and also to view themselves as advocates. Rebecca, stated, “We have the ones [Latino families] that their cultural beliefs, they are still very much the belief that, ‘Well the educator is the expert and I need to go with this,’ so out of respect they won’t push it too much.” Lastly, Paula described challenges working to support migrant families who did not seem to understand or prioritize compulsory education due to seasonal work and mobility: “I have to explain many times, you know, that here, your kid when they turn five, they have to go to school. That is not an option.”

Focus on language supports. We already reported on the persistent lack of language accommodation (i.e., professional interpreters and translated materials) in many schools. Certainly, linguistic access should be a priority. However, other language-related barriers also need to be addressed. Hector, among others, described a need for additional resources and training around language supports for PTI staff who work with CLD families: “I’ve gone to regional trainings [with other PTIs] and there’s not too much support for people who work with families with language barriers. ...The people that work with families that don’t speak English, that’s one of the major gripes that we have. We need more support in providing information to families other than English.” One of the frequently mentioned challenges beyond language access issues was that several special education terms did not exist conceptually or have a direct translation in other languages. Thi spoke repeatedly about this, explaining that she could not just translate them into Vietnamese but also had to define and explain terminology such as

"advocate", "inclusion", and "guardian". Similarly, Paula, who supported Latino families, explained, "You need to learn. I have the glossary of terms in Spanish so, you know, I try to explain it."

Additionally, several participants mentioned other difficulties experienced by CLD families. For example, some participants mentioned a lack of cultural awareness related to multiple dialects within language (e.g., Cantonese and Mandarin). As such, a school may provide a "Chinese" interpreter who only knows Cantonese for a family who speaks Mandarin resulting in a barrier despite intentions of access. Lastly, while all of the participants emphasized the legal and ethical obligation of schools to provide language access to CLD families, many participants also emphasized supporting CLD families to learn English. Participants suggested that learning English would help improve the advocacy of CLD families. Zineb was the most direct in her focus on improving communication skills when she stated, "I'm pushy, but I said, 'Put the remote down. You have to learn English. I can attend one, two, three, four IEPs with you but I cannot be there forever.'"

Discussion

In this study, we examined PTI staff members' perceptions of serving CLD families of children with disabilities. The thematic analysis yielded critical strategies PTI staff members described striving to employ, as well as barriers to educating and empowering CLD families that they face. We had three main findings. First, we found that PTIs have identified ways to overcome the lack of time, staff, and funding necessary to educate and empower CLD families by developing parent leaders. Notably, the field of special education advocacy is growing (Burke, 2013). Agencies are developing and implementing advocacy trainings to increase the availability of advocates to help families access needed services for their children with

disabilities. Although most advocacy trainings lack a focus on CLD families, recently, some new trainings have been developed to improve capacity with respect to specific CLD populations. For example, Burke et al., (2016) tested the Latino Parent Leadership Support Project, an advocacy training for Latino parents of children with ASD. Further, Pearson (submitted) developed and testing the FACES project to test an advocacy training for African American parents of children with ASD. As such, it seems that the PTIs along with other agencies have recognized the need to develop parent leaders to effectively serve CLD families.

Second, we found that PTIs struggle with addressing external, systemic barriers which influence CLD families. Notably, such barriers included the attitude of the school toward CLD families as well as competing and complex barriers among CLD families (e.g., trauma, lack of transportation). Previous research has similarly documented that schools may have negative perceptions of CLD families (Harry, 2008) and that CLD families may have competing barriers (e.g., poverty, Emerson, 2007). This study extends the literature by confirming the presence of such barriers but also demonstrating the need to shift to a positive perspective about CLD families. Previous research has primarily viewed CLD families using a deficit-based framework (Harry, 2002). However, based on this study, it seems that PTIs recognize that CLD families can acquire and benefit from social and cultural capital (Trainor, 2010), and that the barriers CLD families face are not due to cultural deficits but rather due to systemic barriers.

Finally, we found that it is important not to interpret our findings with respect to specific cultural groups but rather to consider the commonalities and differences among diverse parents when trying to educate and empower families. Previous research in special education has neglected to examine cultural differences (Burke, 2012). Further, of the limited extant research about CLD families, research has focused on individual cultural groups (Wolfe & Duran, 2013).

Such studies provide an initial understanding of the experiences of individual cultural groups. However, our study also shows that there are some common themes (e.g., emotional needs, perceptions of disability, language challenges) across cultural groups that could be addressed when educating and empowering CLD families. While these themes may manifest in culturally specific ways, many themes appeared to be consistent across various cultural groups, indicating potential areas for intervention.

Given the lack of human resources and funding among PTIs, this finding is especially poignant. A main mission of the PTIs is to be staffed by parents of children with disabilities—primarily parents who reflect the population to be served (including CLD families). However, it may be difficult for PTIs to hire parents from each cultural group they serve. Our study highlights that PTIs have identified common threads among specific cultural groups. By identifying such commonalities, PTIs may be able to differentiate their assistance to better meet the needs of individual families.

Limitations

Although this study provides a jumping off point, there were also a few limitations. First, this study is limited to PTI participants from five states. The findings are thus limited to these states as PTIs in other states may experience different issues with different populations of families. Additionally, while our findings were representative across participants, a larger sample may result in greater variability of responses. Second, this study lacks the perspectives of other individuals (e.g., CLD families, school professionals). By only focusing on the PTI perspective, we have rich findings in relation to their experiences but not in relation to a holistic understanding of parent advocacy among CLD populations.

Even in light of these limitations, this study has important implications for research, policy, and practice. As students with disabilities become increasingly diverse (Albrecht et al., 2011) and service disparities persist with respect to CLD versus White, European American children with disabilities (Magaña, 2013), it is necessary to develop a toolkit of ways to educate and empower CLD parents of children with disabilities. This study sheds some initial light on strategies to educate and empower CLD families as well as directions for researchers and practitioners to target barriers necessary to be overcome for CLD children with disabilities to access needed services.

Directions for Future Research

This study begins to shed light on how PTIs work with CLD families. However, to better understand this phenomenon, it is important that future research also reflect the perspectives of CLD families who work with PTIs as well as school professionals who have interacted with PTIs. The act of advocacy is bidirectional; actions of the parent depend on the actions of the school and vice versa (Weiss, Lopez, & Rosenberg, 2010). To have a more holistic understanding of the strategies of PTIs and their effectiveness in working with CLD families, it is necessary to include CLD families and school professionals in future research. Future research should also include a focus on PTI support for CLD families with children aged from 0-5 and from 22-26, as PTIs are required to serve these students. This study focused predominantly on CLD families of school-aged children from 5-22.

Further, this study identified several core strategies PTIs employ to educate and empower CLD families; future research should test these strategies to determine their effectiveness. Unfortunately, although PTIs have assisted with research projects, few research studies have determined whether PTI strategies are effective (Burke, 2015). By understanding whether these

strategies result in children receiving better services, the strategies can be identified as best practice. Not only should research test these strategies but also it is important to identify whether there are interactions—specifically, are certain strategies more or less helpful depending on individual or family characteristics? Research is needed to objectively determine the effect of these strategies.

Implications for Policy and Practice

These findings provide support for the critical role of PTIs in educating and empowering CLD families to advocate for their children with disabilities. This is a central part of their mission and they operate at the intersection of special education policy and community organizations supporting CLD families (but not in special education per se). To meet the intensive need for conducting community outreach and targeted recruitment of CLD families, PTIs should hire and/or assign additional staff to work with CLD families. Especially given that CLD versus White, European American families do not initiate contact with PTIs as often (Cooc & Bui, 2017), it is necessary for PTIs to have more resources for reaching out to CLD families.

Further, our findings point to a more complicated and longer process of supporting CLD families to advocate. To meet the demands of educating and empowering greater numbers of CLD families, PTIs across the country should develop systems for sharing knowledge, strategies, and training models. PTIs with effective training models should replicate and share them with others. In particular, PTIs should build a library of translated materials and resources that all PTIs could access in order to lessen the need for each PTI to hire staff from every cultural and linguistic background of the families they serve. Finally, to address the school systemic barriers hindering the ability of PTIs to educate and empower CLD families, PTIs may consider expanding their scope to increase trainings for school personnel. Collaboration between PTIs and

local education agencies around professional development could yield exciting opportunities for practice-based training and engagement in home-school partnerships.

Table 1 Participant Demographics

Name	Race/Ethnicity	Languages Spoken (other than English)	Child's Disability*	Years of experience	Families Served
Zineb	Northwest Africa	French, Arabic, Darijja	ASD, OHI	6	Arab families (primary); African American families
LaTonya	African American	---	ASD, LD, ID	16	African American families
Paula	Latina	Spanish	ASD	9	Latino families and migrant families
Melissa	White	---	LD, OHI	9	African American families and Latino families
Thi	Vietnamese	Vietnamese, French	ASD	6	Vietnamese families (primary); Arab, Haitian, and Indian families
Alba	Latina	Spanish	---	2	Latino families
San	Chinese	Chinese	DD	5	Chinese families
Rebecca	Latina	Spanish	ASD	9	Latino families
Manisha	Asian (India)	Hindi, Gujarti, Punjabi	DD	7	South Asian families
Darlene	White	---	DD	15	African American families
Peg	White	Cantonese, Spanish	ASD, LD, OHI	5	Asian families and African American families
Hector	Latino	Spanish	ASD	7	Latino families (primary); Arab, Portuguese, and Ukrainian families
Kadejah	African American	---	ASD	6	African American families and culturally diverse families

* ASD refers to autism spectrum disorder; OHI refers to other health impairment; LD refers to learning disability; ID refers to intellectual disability; DD refers to developmental delay

Appendix 1.

Semi-Structured Interview Protocol

We are about to begin our interview. Before we begin, please remember that all responses here are confidential. To that end, we will not be using names in any of the products that result from this research. Feel free not to answer any questions. You can withdraw from the interview at any time. The purpose of this interview is to discuss your experiences in empowering and supporting culturally and linguistically diverse (CLD) families of children with disabilities. CLD is broadly defined to include culturally and linguistically diverse families including families from different racial/ethnic backgrounds, low-income families, and undocumented families.

A. Tell me a bit about yourself:

- a. What do you do? Probe for specific job title and description.
- b. How did you get involved with the Parent Training and Information Center?
 - i. If a parent of a child with a disability, tell me a little bit about your experiences in special education.
 - ii. If an immigrant, tell me about how and when you came to the United States.
- c. How would you describe your cultural and ethnic background?
- d. Where do you primarily support CLD families (city versus suburbs)?

B. Experiences Supporting and Empowering CLD families

- a. Tell me about your experiences supporting and empowering culturally and linguistically diverse families (CLD) of children with disabilities. Can you walk me through the process from beginning to end with a CLD family?
 - i. Are there any common themes among your experiences with these families?
 - ii. Was there any one experience that seemed different than the rest?
 - iii. How do you think your background has helped influence your ability to empower CLD families?
 - iv. What barriers do you think CLD families face in receiving services?
 - v. What barriers do you face in empowering CLD families?
 - vi. What strategies are most effective for you as you empower CLD families?
- b. How do you connect with or conduct outreach with CLD families?
 1. What strategies do you use in reaching out to CLD families?
 2. What barriers do you face in reaching out to CLD families?

C. Training

- a. What training did you have to prepare you to support and empower CLD families?
- b. What other supports or strategies would you encourage other practitioners to use to support and empower CLD families?

Concluding the interview:

Thank you so much for taking the time to answer these questions—we really appreciate it!

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