Title

Building a culturally-responsive, family-driven early childhood system of care: Understanding the needs and strengths of ethnically diverse families of children with social-emotional and behavioral concerns

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Introduction

Families with young children (ages 0-5) experiencing or at risk for social, emotional, and behavioral problems have unique challenges when faced with caring for their child. This is particularly true for ethnically-diverse families. There are disparities in the prevalence of risk for mental health issues for children of color and/or children from low-income families (Cooper, Masi, & Vick, 2009). Children of color or those from low-income families may also be under-diagnosed (Tolan & Dodge, 2005). Additionally, there are disparities in the accessibility and acceptability of culturally and linguistically appropriate, high quality mental health services (Turner, Jensen-Doss, & Heffer, 2015). Thus lower-income children of color have a higher need, due to both elevated prevalence of mental health issues and underutilization of health services (Bringewatt & Gershoff, 2010). African American and Latino children have the highest unmet needs, including receiving specialty services (Huang et al., 2005).

California is at the forefront of the demographic transformation the United States is undergoing, and as such, can be a harbinger of the challenges and opportunities this brings. As of 2015, California was a majority-minority state, with Hispanics or Latinos outnumbering non-Hispanic Whites (US Census Bureau, 2016b). In the United States, it is projected that this shift will occur around the year 2044 (Colby & Ortman, 2017), although enrollment records in US elementary and secondary schools indicate that among those under age 18, non-Hispanic Whites are now in the minority (Snyder, de Brey, & Dillow, 2016). In advance of this national shift, the early childhood mental health systems of care need to better understand and address the unique needs of culturally and linguistically diverse families through culturally-responsive and effective behavioral health care services.

Alameda County, California, is one of the most ethnically diverse regions in the United States with glaring inequities (Beyers et al., 2008). In 2016, 31.6% of residents were Asian, 22.6% were Hispanic, and 13.3% were African American (US Census Bureau, 2016a). Each group is diverse with numerous countries and cultures represented. Among the 97,000 children under five in Alameda County (US Census Bureau, 2016a), between 9% to 14% may be at risk for developing social-emotional and/or behavioral problems (Brauner & Stephens, 2006). Further, the region has experienced shifting housing patterns and increased housing costs, which has disproportionately impacted people of color (Schafran, 2013). For many families this has meant an increase in housing instability, food insecurity, increased overall stress, and economic hardship; all of which are negatively associated with early childhood social-emotional and behavioral functioning (Belsky, Moffitt, Arseneault, Melchior, & Caspi, 2010; Park, Fertig, & Allison, 2011; Yoshikawa, Aber, & Beardslee, 2012).

In response to these macro dynamic shifts locally and nationally, children's systems of care must accordingly improve to accommodate the unique needs of diverse families through the provision of culturally-responsive care. As of 2003, Alameda County Behavioral Health Care Services (ACBHCS) has collaborated and contracted with 17 community-based mental health providers to provide clinical and support services to children 0-5 who have experienced social, emotional, or behavioral challenges (ACBHCS, 2018). With such an expansive network, deliberate and ongoing efforts must be made to ensure all families are able to successfully navigate the system. Further, the care that families experience should be responsive to their cultural and linguistic needs. A family-driven system of care, if aligned with the diverse needs of families, can lead to more efficient and effective care (Miller, Blau, Christopher, & Jordan, 2012). In order to ensure services are aligned and responsive to family needs, however, those needs must first be identified. Additionally, services should also be designed using an asset-based approach, harnessing the many sources of strengths and resilience among diverse families.

As such, the Alameda County Behavioral Health Care Services, in partnership with First 5 Alameda and other organizations received funding from the Substance Abuse and Mental Health Services Administration (SAMHSA) from 2009-2015 to transform the early childhood system of care in Alameda, California. At the center of this effort early on, was an emphasis on ensuring the system of care was responsive to the present, and future needs of diverse families. As part of this participatory needs assessment and strategic planning process, Early Connections began by grounding themselves in a comprehensive understanding of the current system of care, as experienced by families receiving services. This effort aligned strongly with the family-driven, data-driven, and culturally and linguistically responsive core principles of Alameda County's System of Care (SOC).

In this paper, we present results of the family focus groups, which were conducted as part of the larger participatory system of care needs assessment to inform system-wide strategic planning and decision-making.

The Current Study

In August-October 2012, five focus groups were conducted with racially and culturally diverse family members of young children with social-emotional and behavioral concerns to explore issues related to children's mental health services. The purpose of the focus groups was to hear directly from family members whose children had received early childhood mental health services, as to what they identify as the greatest needs and strengths of their children, families and the services/system.

The study was designed to achieve the following aims: (1) to identify the needs associated with being a caregiver of a young child (age 0-5) with or at risk of social-emotional or behavioral problems, (2) to highlight the distinct strengths of these families and the communities they are nested within, and (3) to make data-driven recommendations for system and practice improvement, as prioritized by the caregivers of these young children.

Family members were involved in all aspects of the needs assessment, partly serving as research assistants on this project. They worked in conjunction with the research team to collectively develop the focus group questions and protocols, including deciding on appropriate participant incentives. They assisted in recruitment efforts by co-creating and translating outreach flyers in multiple languages, engaging culturally-diverse family members. They were also actively involved in the focus groups, often serving as co-facilitators, and creating a comfortable space whereby participants felt safe being candid about their experiences.

Intrinsic in the work undertaken by the Early Connections initiative is four values previously articulated by Ochocka, Janzen, and Nelson (2002) as central to a Community-Based Participatory Action Research (CBPAR) approach. These include: consumer empowerment, supportive relationships, learning as an ongoing process, and social justice. This study, as nested under the broader Early Connections initiative, utilized the CBPAR framework as well (Nelson, Ochocka, Griffin, & Lord, 1998).

Methods

Given the aforementioned priorities of the overarching initiative which included engaging and empowering those who are most impacted by the system of care, a community-based participatory approach was utilized. Throughout all activities involved in the design and implementation of this study, individuals representing the racially, ethnically, and linguistically diverse patient populations most impacted by early childhood systems of care were engaged. Participants were provided an incentive to enroll: a $10 Starbucks or Safeway gift card. The WestEd Institutional Review Board approved this research.

Participants

Focus groups were conducted with parents whose children had demonstrated social, emotional, and/or behavioral problems; some grandparents or other family members participated as well (*N* = 65). Purposive sampling was used in order to ensure each focus group had 8-15 participants and had representation from a specific racial/ethnic group. Flyers were sent via various methods, online through provider or community listservs or Yahoo groups, or paper copies were posted, distributed or discussed at staff meetings at various community-based mental health provider offices. The focus groups included one mono-lingual Spanish-speaking, one Chinese-speaking (specifically, Cantonese, the main dialect used in the San Francisco Bay Area), one Vietnamese-speaking, and two English-speaking groups. Of the 65 total participants, 20 (30.8%) were African Americans, 19 (29.2%) Chinese, 12 (18.5%) Vietnamese, 7 (10.8%) Spanish-speaking, and 5 (7.7%) of mixed ethnicities. The majority of the participants had young children under the age of 5 currently receiving Medicaid-funded mental health services, who had a range of types and severity of developmental issues and/or socio-emotional. About 20% were older parents or grandparents whose children had received services in the past. Both perspectives were highly valued. No additional demographic data were collected in an effort to protect the confidentiality of participants given the sensitive nature of the topic, and the relatively small sampling frame. All participants resided in Alameda County, California.

Procedures

Five focus groups, lasting between 1.5 and 2 hours, were held in the summer of 2012, as part of a year-long needs assessment process. Focus groups were generally co-facilitated by an evaluation team member and a family member who had lived experience with the early childhood system of care. The use of a co-facilitator, particularly one that participants may regard as a cultural insider, is particularly important when discussing a topic that can be considered sensitive or “taboo” (Padgett, 2016). Both facilitators were deeply grounded in and had capacity in implementing the best practices associated with conducting focus groups with diverse populations (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2007). In groups conducted in a language other than English, a co-facilitator that spoke the same language as the group members served as a translator. For the Spanish-speaking group, a Spanish speaking field interviewer as well as an official Early Connections translator assisted. Food and drinks were provided at each group. The focus groups were conducted at the provider or community sites, with permission, where participants normally received services or met. The providers were willing, valued capturing the families’ perspective, and were highly collaborative with the research team and Early Connections system throughout the process.

During the focus group, participants were welcomed, and provided with an overview regarding the purpose and structure of the group. The participants were informed that all information shared will be kept completely confidential. The co-facilitators then led participants through a semi-structured focused conversation protocol. Questions focused on the most significant challenges facing young children with mental health needs, the type and availability of services needed, and barriers to the receipt of services. Additional probes were also used for clarification, and to expand on themes that arose during the groups. See Table 1 for the full interview protocol. Focus groups were audio recorded, and later transcribed for data analysis.

Analysis

For the analysis of the focus group transcripts, members of the research team (Authors 1, 4, and 5) conducted two cycles of coding. For the first cycle, initial coding was used to identify themes and patterns within and across groups, organized by question or outcome area of focus. Initial coding is an iterative approach which is closely aligned with a grounded theoretical approach to data analysis (Saldaña, 2015). Following the initial cycle of coding, the codes were reviewed by Author 1 prior to proceeding to the second cycle of coding. From there, it was determined that two separate coding strategies were needed for the second coding cycle, given the different study aims. The second cycle of coding was completed by Author 2 in consultation with Author 3.

For Aims 1 and 2, which focused on the needs and strengths of families, focused coding was used, as it is well suited for studies applying a grounded theoretical approach (Saldaña, 2015). Focused coding was used to identify major themes emerging from the data, across the questions posed to participants. For Aim 3, given that participants were asked to give specific recommendations for services, a more thematic-driven coding strategy was used. Pattern coding is well suited for identifying meta-codes, or major themes across smaller units of analysis (Saldaña, 2015). In all instances of coder disagreement, consensus was achieved through discussion among the data analysis team. Once the data analysis was complete, the study team engaged parents and other Early Connections SOC stakeholder to validate and interpret the findings as needed. The summaries were drafted, again soliciting their feedback and collaboratively preparing community-friendly results for dissemination and data use by the system of care, and community members. It is important to note that the lens and capacity of the research team to use a participatory, family-driven, culturally and linguistically-sensitive methods were critical to ensure more valid and reliable findings.

Results

Findings from the participant focus groups are presented below. Strengths are listed first, starting with those on the micro level, then continuing to the mezzo and macro levels. Challenges will then be presented, again organized from the micro, mezzo, then macro levels. These will be followed by the recommendations of study participants on to improve the early childhood system of care. Each one of these themes encapsulates the perspectives of participants from all cultural or linguistic groups, unless otherwise indicated. In instances where one specific group had a distinct perspective within the theme, that is explicitly identified within the theme.

Several themes emerged during the focus groups, highlighting needs and strengths from a family caregiver perspective. Wellness was expressed as an overarching goal for the families; across all focus groups caregivers expressed a great deal of love, pride and hope when speaking about their children. The participating parents, like most parents, said they wanted to see their children receive a good education, improve their communication skills, gain independence, experience happiness, be “normal”, and have successful careers.

Family, Community and System-level Strengths

An explicit focus on better understanding strengths and assets of the children and the families, that could be leveraged to address their needs, was an important part of this needs assessment process. In fact, strengths-driven was one of the underlying principles of the systems of care, and an overall framework for the evaluation and research team.

Focus on child’s positive social and emotional development. Across all focus groups, participants expressed a great deal of love, pride, and optimism when speaking about their children, with distinct visions of their child’s development and future. One participant described her hopes for her child:

> *I just want my kids to be men and women of character, to have strong, strong convictions of who they are and the decisions that they make. To be culturally sound and know where they came from. And to just make good choices.* Participant, African American focus group #2

Participants also expressed an optimism that they could help their children overcome some of the aforementioned fear and negativity experienced outside the home, through the construction of a solid foundation in love and values.

Emphasis on child's life opportunities. In addition to social and emotional development, participants also reflected on their hopes for their child's future, particularly in relationship to the quality of education they receive and types career opportunities they have. In the Cantonese and Vietnamese-speaking groups in particular, the caregivers focused on a desire to give their children the best education available. Parents across all groups expressed their hope that children could improve their communication skills, gain independence, experience happiness and be "normal", and have successful careers in whatever they decide. One Spanish-speaking participant shared her aspirations for her child: "*I want her to become independent. I want her to be able to have a career and to be able to realize her dreams*."

Community connectedness. Participants across all groups indicated that they felt connected and supported by other families in their community. This was often manifested in the general support they received from each other, such as watching over each other's children. As one parent voiced, "*You've got a community out here. There [are] people that love each other."*- Parent, African American focus group #2.

Culturally-responsive services. Finally, while participants indicated a need for more culturally-responsive services, they also expressed an appreciation of the diversity of existing services, particularly when delivered by a provider whom they can trust. For focus groups held in a language other than English, participants also indicated a desire for, and appreciation of, providers that spoke their native language. For example, one participant in the Cantonese-speaking Chinese focus group noted numerous positive aspects of mental health services including cultural sensitivity, provider patience, and the availability of services in multiple languages. Another participant from the Cantonese-speaking focus group described how linguistically and culturally-tailored services helped her family's transition as new immigrants:

"…when we came to the United States, we don't know the cultural background of other ethnicities so it is hard to learn from them. I feel that we can communicate with each other here."

Community organizations and activities. In addition to individual and familial-level factors, participants also saw numerous elements of their broader communities as a strength. Participants expressed appreciation for activities such as museums' free days and events held in local parks. They also cited the value of institutions and organizations in their communities such as libraries, churches, police, and schools.

Family Needs and System Challenges or Gaps

Participants across all focus groups were asked to reflect on some of the challenges they faced in providing care to a child with social, emotional, and/or behavioral health needs. In some instances, these included challenges they experienced personally as the primary caregiver. Other challenges were identified related to patient/provider communication, as well as organizational, and societal-level factors. The following represents themes that arose across all focus groups. In instances where specific racial or ethnic groups identified unique themes, or where those themes resonated more with specific groups, that is indicated accordingly.

Family-level challenges and needs.

Unmet basic family needs. Participants identified a number of challenges associated with ensuring their children received adequate behavioral health care; these challenges were exacerbated by struggles to meet basic needs for food, housing, and employment. These specifically included: limited finances, high medical expenses, nutrition, inadequate childcare, and finding time for their child and job. A few talked about having limited transportation to get to/from appointments, school, and other places. Not being able to afford quality child care was a major concern; many stayed home to take care of their children rendering them unable to work, and unable to afford quality housing and soaring living expenses.

Parental Chronic Stress: Parents expressed high levels of stress, as one of the biggest challenges they faced. They also indicated multiple ways that stress can impact parenting.

> *When the family is under stress from the time, for whatever reason, whether it's not having a job, or not knowing where they are going to live, or have their own mental health issues, or anything like that, it's harder to not just pay attention to your kids needs but also be emotionally… basically be there with your kids.*
>
> Participant, Spanish-speaking focus group.

The need for emotional support for parents from both other parents as well as from providers, was echoed in every focus group.

Patient/provider factors.

Provider-parent relationship: The need for caregivers to be heard and respected. Many participants discussed a fundamental need to be heard by their children's care providers, to know they will get help when they ask for it, and to be more informed about their children's health and wellness. This was identified as a need regardless of the participants' native language, indicating a frustration that was not necessarily grounded in being understood as a result of language barriers, but rather a need to be truly heard. Participants expressed frustration in feeling that providers often were not listening to or respecting them, and as a result felt that their and their child's needs were not met. One parent in the Spanish-speaking focus group discussed the importance of having an advocate to be heard and to receive help: *"(they) have to hear from a professional… not every child on this earth has a social worker!…They won't listen to me as a parent. So they fall through the cracks. You know? And it's very frustrating.*" Many mentioned that their child had to have received a diagnosis or had to fail first before anyone would listen or provide mental health services.

Focus group participants also indicated feeling as though providers have a lack of respect for their knowledge as caregivers. As another parent in the Spanish-speaking focus group put it, "*they need to start with respecting the parents when they talk to them and they hear them, and listen to them. Because who would know better than parents?"* Alternatively, another parent described a positive experience with a provider, and how that led to a better working relationship:

> *The one time when I did have a good experience with my pediatrician was when he actually listened to me, and asked probing questions about my child. Not just his behavior, but he was also looking at possible health issues that could relate to his behavior. He didn't just look at the chart and this is why…oh, we have another one of these kids, or whatever. He actually looked at the chart and said, 'there are a lot of unanswered questions,' which I really appreciated.* –Participant, Spanish-speaking focus group

Limited resources and supports for parenting. Participants expressed uncertainty about how to work successfully with their children, and indicated a need for support and guidance in this regard. In particular, participants indicated a need for help in addressing their children's social, emotional, and language development, irrespective of the family's language spoken at home. They also sought more information about how to improve their children's behavior, when to use discipline and when to be lenient, and how to let their children make their own decisions. When asked about their most pressing needs, one participant in the Vietnamese-speaking focus group stated: "*I need more information, knowledge, answers about what are some good ways to help my child learn."*

Unclear communication /information sharing regarding child's condition and treatment. Participants expressed a desire for improved and increased communication from their provider. One particular domain this was discuss in relation to was their children's diagnosis or prescription medication. In some instances, participants felt that providers were quick to prescribe a pill or conduct an evaluation without getting to the heart of the problem. One Spanish-speaking parent recounted a story of receiving Prozac for her child without an adequate explanation from the pediatrician. *"[They] wouldn't tell me why they were prescribing it. They were like, 'Prozac. You know, psychotropic-type medications,' and I had no idea why, and the doctor never explained to me why."* Participants also indicated that more open communication with providers and involvement in their child's care could also help them identify when there is a problem, and to advocate for necessary services.

System-level challenges/gaps.

Fragmented/uncoordinated service system. Participants indicated frustration at the lack of comprehensive services in a single location, and the resulting difficulty associated with receiving help for their child's emotional or behavioral issues from a pediatrician. One participant in the Spanish-speaking focus group described one such instance, asking the pediatrician: "…'*Do you do in-home assessment? You know… doing an assessment for little kids about emotional stuff?' and they don't*." Other participants cited experiences where the pediatrician either indicated they did not feel equipped to address the child's emotional or behavioral needs, or was unwilling or unable to provide an appropriate referral.

Difficulty accessing services. Participants also expressed frustration with the lack of information they received related to service access and availability. As one Cantonese-speaking participant described: "*I did not know there are these kinds of services and did not know where to find them."* Participants also discussed how this resulted in difficulty navigating the mental health system and utilizing the resources in the Regional Center (which is a hub for anyone with developmental disabilities serving a specific region within California) and other related programs. Some felt this lack of information was inextricably connected to their feelings of not being heard or valued. They stated:

> *It would be nice if, not only would they respect us as parents in terms of being experts in our children, but also respect us enough to share information with us, so that we can, you know, know what to do or where to go*. –Participant in Spanish-speaking focus group

In discussing a possible solution to navigating the SOC, one participant in the Vietnamese-speaking focus group suggested family navigators: "*A family educator coming and helping us navigate through the system would be good*."

Need to expand culturally diverse social services. Participants indicated a need for services that could address their child's social, emotional, language and behavioral development in culturally-responsive ways. Some participants spoke about the importance of receiving culturally appropriate services. Participants in the non-English speaking groups identified a desire for a provider who speaks their language and whom they can trust.

Community-level factors.

Self-imposed caregiver blame. Participants recounted receiving both explicit and implicit messages about their accountability for their child's emotional or behavioral problems, which often led to feelings of responsibility, guilt, and embarrassment. One participant in the Spanish-speaking focus group recounted an experience when they were explicitly told *"The reason why my son was behaving as he was, was because me - as a parent (I) wasn't doing my job."* This may lead parents to feel shame, as one Cantonese-speaking participant described: "*for some people, they feel embarrassed. They say my son is doing this, and feel embarrassed*." Another Spanish-speaking parent described how this often results in a delay in seeking care:

> *For years, my son had these behaviors that I didn't realize were related to mental health issues because, you know, I was told that he was this bad kid and I'm a bad parent, and I'm not parenting him properly*.

Participants also indicated that when they did eventually seek mental health services, they felt they were perceived as "the bad guy," which also has implications for patient/provider communication.

Mental health stigma. Parents and young children at risk for social-emotional, or behavioral challenges often felt stigmatized by peers as well as by broader society. For participants in the African American focus group, this was strongly emphasized. They were acutely aware of the negative connotation of the mental health label, particularly in light of how the many other negative labels African Americans encounter. A parent in one of the focus groups with African American caregivers reflected this when speaking about his son's hesitation to use mental health services at school: "*My son, they have mental health services in our school. Right? My son, he doesn't want any of it, because it's like labeling*." African American participants in particular discussed feeling that their kids are "reconstructed" outside of the home in ways that they were hard-pressed to control.

Social injustice*.* Social injustice is another theme that arose in multiple focus groups, but was particularly underscored in the African American focus groups. In these, several participants identified social injustice as the root of mental health problems in their community. They expressed anger and frustration with systems they described as racially unequal, such as job qualification requirements that disproportionately exclude African Americans from positions in schools and community organizations. One participant elaborated: *"…now I'm talking to the mental health counselors, and … [they're] not helping...it's not anything necessarily wrong with* *their mind; it's society in general. And mental health cannot fix that."* –Participant, African American focus group #1

School safety and quality. Finally, participants discussed the need for safe and high-quality schools. One participant in the Vietnamese-speaking focus group was very succinct when describing her most pressing priority: "*I want a better school for my child*." Another African American participant reflected this emphasis on school quality, and expressed concern about how that might impact their child's opportunities: "*…our schools are not equitable. Children of color are not taught to be successful like other children are."* The importance of safety was especially predominant in the focus groups with African American parents. One African American parent told the group that his son asked him: *"Dad, why do you want me to go to school? Everybody up there is just getting killed. Why are you trying to send me up there?"*

Recommendations for Improving the Early Childhood System of Care to Meet Family Needs

Finally, participants expressed a number of strategies at the system and provider levels to improve the early childhood system of care in order to better meet their needs. It is critical to capitalize on and empower the school and organizations as well as the parent community to better support young children at risk for social-emotional and behavioral concerns.

Provide more support services for caregivers. Participants indicated a distinct need for more support from peers as well as from professionals, and they brainstormed some possible ways that systems of care could facilitate that. While the focus and emphasis of early childhood care is often on the child, parents and other caregivers felt that they would benefit from direct services or service linkages themselves. One way they suggested that individual agencies or the Regional Center could facilitate this was by providing a time and place where parents could meet. This could include gatherings with other parents along with their children, such as playgroups. One participant in the Cantonese-speaking focus group described how this informal peer networking would be beneficial: *"Parents can exchange ideas. With similar problems, we can see how to solve them. Especially when the children are young, we can learn from others' experiences on how to take care of our children."* Another Cantonese-speaking participant agreed: "*We need more play groups. It will be good for parents and good for the children and grandparents, then we can learn more for a healthy body and healthy mind."*

Participants also discussed some possible benefits of meeting other caregivers without their children present, such as in a caregiver support-group. This could give caregivers an opportunity to support each other by exchange experiences, and brainstorming solutions for issues that may arise. This could also provide a venue through which caregivers could connect, vent, work through anger, and generally receive support. Participants indicated an interest in having a centralized agency that could coordinate referrals to adult-serving systems, to help them meet their emotional and financial needs.

Integrate mental health with developmental health and physical health services. As mentioned, in several focus groups attendees indicated a frustration with the structure of mental health services. They felt that opportunities for early-identification (i.e. developmental screenings at routine pediatric check-ups) were often missed, thus suggesting screening tools could be more consistently and proactively utilized by pediatricians or health services. When problems were identified through assessment for instance, they also felt that physical and behavioral health services seemed disjointed, resulting in a less efficient, and effective system of care. In cases where they did receive referrals or were made aware of specific programs, this often came from integrated medical practices. One Cantonese-speaking participant described how she found culturally-responsive services: "*I asked my son's family doctor and the social worker referred me here*." Participants felt that by more seamlessly integrating care, ensuring medical practices had staff available to provide appropriate referrals and/or provide services directly to families, they would be better served.

Provide developmental and behavioral health training for childcare workers and teachers. Training staff in childcare and elementary school settings was also discussed as a strategy for the early identification of social-emotional and/or behavioral problems in young children. As one Spanish-speaking participant stated "*I would want a teacher to know about child development. You're working with 2-, 3-, 4-year-olds, you should know something*." Recommendations included training childcare workers, teachers, and clinicians at school sites to recognize social-emotional or behavioral challenges that might arise. This would not only ensure that young children received care earlier, it may also work to reduce inequities in access to clinical services.

Improve provider capacity to more effectively communicate and work with diverse families. Throughout the focus groups, multiple participants from various racial and ethnic groups described both positive and negative interactions with providers. The tone of these interactions often set the foundation for the working relationship that parents and providers developed. Participants valued practitioners that asked them questions, and took time to really listen to them. They recommended that providers be trained in how to most effectively have these conversations, particularly with racially, ethnically, and linguistically diverse families. Similarly, they also indicated the importance of training other professionals to engage caregivers in more meaningful, mutually respectful ways including school staff, therapists, and other relevant providers.

Put families in control. Participants emphasized the importance of ensuring that systems reform is done in conjunction with their sustained involvement. To achieve this, they felt that the families must be fully integrated in policy, program and system-level decision-making governing bodies (such as the Regional Center). One participant described what this might look like:

> *I mean, like what about really making space for us at the table to say, here's what we need? We have the ideas, we have the knowledge, we have the expertise. We don't have to have professionals doing it and telling us what we need.* Participant, Spanish speaking focus group

Further, participants felt that families should be reimbursed for their time and participation in such decision-making processes; they suggested agencies seek grants specifically to fund this. Finally, for various paid positions, they emphasized the importance of hiring locally from Alameda County communities, so that community members could directly design and manage the programs and services they most need.

Provide positive safe neighborhood spaces/strengthen community. Participants' recommendations were holistically-focused on their child's, and the broader community's health. Participants expressed interest in having more recreational activities and opportunities to interact with other community members. They also sought safer public spaces for their children to play. One participant from the Vietnamese-speaking focus group stated they "*want(ed) to more places to bring our kids"* however she recognized that: *"more resources are needed."* The broader issue of community safety was also prioritized. Residents were adamant about the need to get guns and drugs out of their communities, to ensure all children had the opportunity to live, grow, and thrive.

Discussion

This participatory study was a critical component of a broader systems change effort to align services into a more efficient and effective system of care in Alameda County. Through this process, parents and other caregivers were able to articulate their distinct challenges and strengths, and their recommendations to agencies and organizations so that they may better serve both their families and their communities. While this study was limited to Alameda County, California, given the racial/ethnic, cultural, and linguistic diversity among participants, findings shed a unique light on some of the challenges and strengths identified by caregivers.

The shared perspectives and experiences of participants is worth noting. It was hypothesized that the themes emerging from focus groups with caregivers from different racial or ethnic backgrounds would be distinct. However, the analysis and resulting identification of themes showed that the caregivers of young children with social and emotional issues had a significant amount of shared perspectives. That is not to say that there were no differences by subgroup. For example, African Americans in particular identified a need to address social injustices, and voiced concerns about the social reconstruction of their children by others. Additionally, among those who were in non-English speaking groups, some distinct barriers to care included communication with the providers, and they identified a need for linguistically-aligned services.

There may be several reasons why the majority of themes were shared by participants across different racial, ethnic, and linguistic backgrounds. We posit that caregivers of young children, particularly those who are low-income in a place with an exceedingly high cost of living, may have much in common as a result of their shared disadvantages. These at-risk characteristics, in addition to caring for high-need children, may supersede many of the cultural differences between them. Future research is needed to explore the intersections of socioeconomic status, race, and ethnicity, particularly as it relates to the challenges caregivers face, and their specific needs for responsive services.

The perspectives captured in this study, highlighted across the diverse participants, resulted in the identification of specific, targeted recommendations that can be used for transformation efforts for early childhood systems of care more broadly. While this represents a relatively understudied area of research, some of the findings herein are reflected in other studies focused on children experiencing social-emotional and/or behavioral problems.

The challenges, strengths, and needs for services, as identified by the participants are presented separately in this study; however, in many ways these three are intertwined. The suggestions they have for strengthening early childhood systems of care were made in consideration of both their unmet needs, and their family or community, service provider, and system strengths. For example, the frustration participants expressed regarding the fragmentation of services was reflected in their suggestion to integrate mental health with developmental health and physical health services. Service integration has long been recognized as a critical strategy to ensuring children are receiving comprehensive services, and there are a number of approaches to providing more comprehensive care (Kolko & Perrin, 2014). A meta-analysis found that the alignment of physical and behavioral health services through integrated and collaborative care, had a significant positive effect on the reduction of mental health symptoms for children and youth (Asarnow, Rozenman, Wiblin, & Zeltzer, 2015). The American Academy of Pediatrics recognizes the need for this institutional shift and has emphasized the importance of pediatricians developing close working relationships with other types of care providers in order to promote child health across the life course (Garner et al., 2012).

Solutions that address these issues once they arise are important, but as participants discussed, it is also critical to ensure mechanisms are in place for early identification both within and outside of medical care. Again the American Academy of Pediatrics recognizes this need, with calls for universal, age-appropriate developmental screening, particularly among populations at greatest risk of experiencing toxic stress (Garner et al., 2012). Other possible strategies for early-identification include training those outside of traditional medical settings. Training child care professionals, for example, is aligned with participants' recommendation to train childcare providers and school staff. This could not only ensure at-risk children with social emotional or behavioral challenges are identified early, it could also ensure care providers are properly equipped to provide them with culturally-responsive, and effective care (Ritblatt, Hokoda, & Van Liew, 2017). This represents an important effort as parents of young children with emotional or behavior disorders report significant stress associated with finding and maintaining high-quality childcare (Rosenzweig, Brennan, Huffstutter, & Bradley, 2008). These trainings, for medical and non-medical providers alike, could also ensure caregivers receive culturally-responsive care, which is another challenge identified by participants in these focus groups.

Findings from this study, taken together, also demonstrate the need to simultaneously address the underlying conditions that create or exacerbate impediments to optimal social-emotional, and behavioral functioning in young children. A mothers' experiences of chronic stress and trauma are associated with their children's social and emotional development, which ultimately puts that child at risk, resulting in a cycle of disadvantage (Folger et al., 2018). Most interventions that focus on early childhood social-emotional or behavioral problems represent a more reactive, or downstream response whereby we treat the symptoms present in young children after they reach clinically significant levels. To reduce the number of children who are at risk, we must take a more upstream approach, focusing on addressing the conditions that these families are nested within. This includes improving neighborhood safety, high quality child care, high-performing schools, and ensuring families have access to stable and affordable housing and preventive community resources and opportunities.

This study was initially conducted in order to inform an early childhood mental health systems change effort in Alameda County, CA. The study was grounded in a CBPAR and empowerment evaluation framework; culturally and linguistically diverse staff were engaged throughout the study, thus resulting in more accurate and reliable findings. In this study, CBPAR was not limited to the study design and implementation, parents and other caregivers were also instrumental in advocating for system's change, as part of the broader Early Connections initiative. Parents' and caregivers' understanding of deeply-rooted culturally-driven values and behaviors in child development played an important role in the study team's interpretation and understanding of the culturally-specific needs.

Further, as a result of the CBPAR framework this effort also became a catalyst for sustained momentum towards change, with parents and other caregivers at the center. Parents and stakeholders worked individually and collectively to carry these findings beyond these focus groups; parent stakeholders synthesized the findings, and used them to advocate for some of these changes they wished to see in their communities, and in the early childhood system of care. The study results, as well as the CBPAR strength-based approach implemented within SOC principles, can inform similar participatory needs assessment and strategic planning efforts in other communities. An integral process, for which sufficient time and resources must be allocated to build upon and sustain an effective principle-driven children's SOC.

Study Strengths and Limitations

Particular study strengths included the use of culturally and linguistically appropriate outreach, materials, staffing, and facilitation methods. This resulted in more honest and accurate results. Sufficient number of participants from within each community group participated, thus ensuring some sample reliability. A strengths-based approach was explicitly used throughout; multi-level factors at child, family, provider and system level were captured, and the CBPAR approach provided more authentic insights and ways to capture collective community voices. Qualitative data from this study was triangulated with other secondary data. This furthered the utility of this data to inform systems of care change, in order to ensure it was family-driven, data-driven and culturally and linguistically responsive.

The study had several limitations. Participation was limited to parents and other family members residing in Alameda County, CA, which may limit the generalizability of the results. Given the wide availability of services in the Bay Area, families may have access to a more linguistically and culturally-responsive services. The diverse sample represents the growing diversity nationally, however; thus findings may be relevant to other similar communities and systems in the country. Additional research with diverse populations living in other regions of the United States is needed, particularly in regions with more limited services.

Furthermore, in some cases, theoretical saturation may not have been achieved in terms of sample within a group. Further, as the purpose of these focus groups was to achieve racially, culturally, and linguistically diverse representation of parents and caregivers involved in the early childhood system of care, in some cases theoretical saturation may not have been achieved. Focus groups were also limited to caregivers who were already engaged in or served by the system of care (hence their perspective was captured); these families may differ in some fundamental ways compared to families not receiving any services, or families receiving private services (i.e. higher income families). Nonetheless, participants in this study are those receiving safety net services, rendering them particularly vulnerable. As such, they may represent a substantial portion of families in need and their perspective may be reflective of those needs and challenges that may be experienced by others across the country, especially as the United States becomes increasingly racially and ethnically diverse.

Conclusion

This study demonstrated that ethnically-diverse family members, who play a critical role as primary caregivers for young children with social-emotional or behavioral concerns, continue to have multiple unmet complex needs and challenges accessing high quality culturally-responsive mental health services. They also have many strengths and assets that must be leveraged. Putting parents at the center of it all, using CBPAR to listen to them and empower them to collectively develop and implement multi-pronged strategies is the only way. They know what their children need better than anyone else. Given limited resources and growing social-emotional and behavioral concerns among our youngest, we cannot afford not to work closely with the growing diverse families to improve the safe and positive places, via integrated culturally responsive systems and policies, for their children to live, learn, play, and thrive. Only then will our early childhood systems of care be able to effectively serve all children equitably.

Table 1. Semi-Structured Focus Group Interview Questions, for culturally diverse groups of family members, Early Connections system of care, Alameda County

Opening

1. Can you tell us your name and share something precious about your child? Probe: one thing that's positive that you've noticed recently.

Children's health and wellness

2. As a parent, what are your biggest hopes or desires for your child's growth? What is your vision for your child? *Probe: Growth could be that the child is more independent, likes to play with children, is expressive, shows concern for others, can talk to adult relatives, etc.*

3. How do you define wellness for your child?

4. In your community or family, what are parent's worries about their child's behaviors? Probe: *Behavior concerns could be that a child is really outspoken, acts out or is really shy or doesn't play with other children.*

5. What are the biggest challenges or obstacles you or your child have faced? What would you say young children and/or parents need the most? Probe: what do young children or their parents need the most?

Role of community and culture

6. What do you like the most about your community? Is there a strong sense of community?
7. How does the community support parents with young children, and especially those who have difficulties? What kind of help or resources do they provide?

Parent's health

8. What kinds of stressors do parents have? How do you deal with those stressors?
9. How about having a safe positive home environment or neighborhood? Meeting basic needs, working? Are these issues you are concerned about?
10. Are existing supports and services sufficient to meet parents' needs? If not, what additional information, resources or supports are needed? Probe: What do you need to better support your child?

Service experience

11. What kinds of services or supports have been most helpful for you? Any programs that have worked really well that we should expand? Probe: can you give an example?
12. What hasn't been helpful? Any major problems with the supports you have received? Probe: MediCal, cultural competence, transportation.
13. What else is needed? Anything you'd like to see changed or done differently?

Family-driven

Early Connections defines Family-driven system of care as "Family members are the authority in making decisions about their children." This includes having family members as part of decision-making at all levels.

14. Would you say the services or care you received were family-friendly, and respected your voice? How so? How can services be improved (to be more family-driven)? By services we mean mental health services/ clinicians/social services/schools.

Future strategies

15. If you could wave a magic wand and change ONE THING about the services your child receives, how they're provided, how you and your child are treated or anything in the system, what would it be?
16. What is your vision for the children in your community? Are there any other changes you like to see in the 3-5 years?

Closing

17. Is there anything else you want to share with us?

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