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A Family-Centered Mixed-Methods Needs Assessment for the System of Care for Young Children with Social-Emotional and Behavioral Concerns

Introduction

Early childhood (age zero to five) is a critical period of development (Shonkoff & Phillips, 2000), and a time when mental health issues emerge. Approximately 9-14% of children age zero to five (Brauner & Stephens, 2006) in the U.S. have mental health issues, but are understudied in comparison to older children. The prevalence of mental health issues may be higher for children from low-income families, immigrant families, and families of color (Cooper, Masi, & Vick, 2009).

Promoting positive mental health and wellbeing for young children can affect their development across the life course (Shonkoff, 2009). However, systems of care are often not structured to support the positive development of young children from low-income families and families of color (Alegria, Vallas, & Pumariega, 2010). These families often are exposed to more risk factors for poor mental health and less access to mental health services (Hodgkinson, Godoy, Beers, & Lewin, 2017). Furthermore, there is a dearth of mental health services that are responsive to their family, community, language, and culture (Turner, Jensen-Doss, & Heffer, 2015). In order to design more effective and efficient models of care, more information is needed on how at-risk families (e.g. those who are low-income, racially or ethnically diverse, non-English speaking, or for whom English is a second language) are (or are not) being served by existing systems.

The Developmental Ecological Theoretical Framework

The developmental ecological theoretical framework identifies myriad factors at multiple levels (e.g., individual, family, community) that can affect young children's mental health (Anderson & Mohr, 2003) and decreased access to services, due to socioeconomic status, immigration status, and their race, ethnicity, or language. Diverse social and environmental exposures can affect mental health (Allen et al., 2014). Drawing from Bronfenbrenner's (1994) ecological model of human development, individual early childhood experiences, as well as the nested effects of family, community, institutional, and societal exposures during early childhood, can all affect emotional and behavioral health. We use this theory to create a framework around which risk and protective factors at each level can be explored, with an eye towards designing and implementing interventions to promote mental health.

Early Childhood Systems of Care

It is important to focus specifically on early childhood systems of care (SOCs), since participating families have different needs and experiences than people participating in systems of care serving school-aged children (Schreier et al., 2019). In response to a growing recognition of children's mental health needs (U.S. Department of Health and Human Services, 2000), gaps in services (particularly those that are culturally and linguistically responsive), and a need for coordinated care (Stroul, Blau, & Friedman, 2010), the U.S. Department of Health and Human Services has funded value-driven children's Systems of Care (SOC) for the last 25 years through the Substance Abuse and Mental Health Services Administration (SAMHSA) (USDHHS SAMHSA, 2016; Stroul & Friedman, 1986). Early childhood systems of care have been identified as having a high return on investment and therefore an important social program to scale (Horen, 2016). Other research identified the following barriers to care within early childhood systems of care: stigma, family engagement, empowerment, and community collaboration (Finello & Poulsen, 2012). The Early Childhood SOC communities have sought to

identify best practices, including strengths-based approaches that prioritize relationships with community stakeholders, and across agencies (Stroul & Friedman, 2011).

Early Connections in Alameda County

As part of SAMHSA's Early Childhood SOC initiative, Alameda County Behavioral Health Care Services (ACBHCS) received funding from 2009 to 2015 to plan and implement Early Connections, an effort grounded in developmental ecological principles to strengthen their SOC for children zero to five. Beginning in 2003, ACBHCS worked with community-based mental health providers to provide clinical and other support services to young children; ACBHCS sought to strengthen this burgeoning SOC and encourage more systematic system integration with the financial and other resources SAMHSA provided for Early Connections (Jain et al., 2019). Early Connections sought to promote and improve wellness for young children and their families by engaging stakeholders at multiple levels (e.g., family members, providers, and key community partners). The initiative's overarching goals included: developing a broad-based governance structure of decision-makers including family members, providers, cross-sector partners, and community members; building early childhood agencies' capacity for cultural and linguistic responsiveness; increasing family members' involvement and leadership capacity; integrating Family Partners to provide support services with the early childhood SOC; forming a Family Member and Provider Co-Learning Collaborative to support family-driven and culturally/linguistically responsive care; and ensuring early childhood mental health services were developmentally informed (Gutierrez-Padilla, Novosel, & Briscoe, 2013). (Family partners are people who have used the children's mental health system and/or related systems in their capacity as family members, and have since been trained more formally, and now work with community mental health providers to complement clinician expertise with lived experiences; Burton, Cohen, & Jain-Aghi, 2014.) The population of focus was children ages 0-5 with, or at

risk of, serious social, emotional and related developmental challenges, with particular consideration given to populations most in need of services.

Alameda County is located in the U.S., in the San Francisco Bay Area's East Bay. The county is racially, ethnically, and linguistically diverse. During the study, the population was approximately 32% Latino, 25% White, 24% Asian/Pacific Islander, and 13% African-American (ACPHD, 2010). Approximately 32% of births were covered by Medicaid (ACPHD, 2010; California Department of Public Health, 2010). Though there has been a major expansion in Alameda County in providing Medicaid-funded mental health services to young children, a significant unmet need of mental health services for young children remains, particularly those who are low-income and from immigrant families.

Early Connections sought to strengthen the SOC to be more effective and culturally responsive. The initiative utilized a collaborative system development cycle that began with the participatory needs assessment, in an effort to increase stakeholder buy-in (Ross & Jaafar, 2006). This paper describes findings from the participatory needs assessment, including gaps in services and system strengths, and presents stakeholder recommendations to improve the system of care.

Methods

Participatory Needs Assessment Approach

To conduct the participatory needs assessment and strategic planning process, the research team worked closely with the Needs Assessment Work Group and the Core Management Team. These groups included family members, SOC partners such as First 5 Alameda and Alameda County Behavioral Health Care Services, mental health providers, and researchers/evaluators. This assessment was deliberately designed to be grounded in stakeholder perspectives, including ethnically-diverse family members, cross-agency and community-based

partners, community-based mental health providers, agency leadership, and other community stakeholders.

Purpose and Aims

The needs assessment sought to identify key issues most relevant for families of children ages 0-5 with social, emotional, behavioral and developmental concerns, and to describe system gaps and strengths as identified by families, care providers, and community stakeholders. This included emerging population needs and current SOC gaps. Our research aimed to: (a) describe the greatest needs and concerns (both directly and indirectly related to their children and the system of care) of family members with a child age 0-5 with a mental or behavioral health problem, and (b) identify strategies for families, providers, and key organizational partners to improve the system of care moving forward.

Data Collection

Qualitative and quantitative data collection methods were used to triangulate findings and minimize bias. Data were collected through original qualitative research, secondary data analyses, and a document review including notes from community meetings and published programmatic reports. All data collection occurred between July and November 2012; all research activities were approved by the WestEd Institutional Review Board.

Focus groups. Racial, cultural, and linguistically diverse families participated in five focus groups (n=65), to identify the needs and strengths of their children, their families, and the SOC (see Author, 2019 for a full description of the methods and findings). Participants were recruited widely and sampled purposively for racial/ethnic diversity. Following a semi-structured protocol, participants described their SOC experiences and identified strengths and challenges related to caring for their children. Focus groups were conducted in English, Cantonese, Vietnamese, and Spanish. The race/ethnicity of participants is as follows: African Americans

(n=20), Chinese (n=12), Vietnamese (n=7), Latino (n=7), and mixed ethnicity or other (n=5). Beyond race, ethnicity, and language, no demographic data were collected to protect the confidentiality of participants, as some may have been undocumented.

Additionally, one focus group (n=11) was held with mental health providers. Participants' duration of employment in their current job ranged from 6 months to 25 years. Facilitators used a semi-structured focus group guide, which included questions about unmet needs as well as strengths of children and families, gaps in the current SOC, and recommendations for strengthening it. Given the small sample size, no demographic data were collected from providers to protect their confidentiality, and so demographic representativeness is unknown.

Interviews. Key informant interviews were conducted with other stakeholders (n=16) including health care and social service providers, school representatives, and the local Special Education Local Area Plan (SELPA). Interviewees were sampled purposively, with the goal of getting diverse perspectives. Questions in the structured interview guide asked participants to describe the current state of the SOC, to compare that to their broader vision of how the SOC could better serve families, and to identify strategies to more closely approximate a strong, well-integrated SOC.

Quantitative data analysis. We conducted descriptive statistical analysis of secondary quantitative survey data to complement the qualitative findings. We used data collected by ACBHCS on families being served, including demographics/family characteristics, and family's basic needs, clinical needs, and child functioning and improvement. Quantitative data are incorporated throughout the results section, to contextualize the study's qualitative findings.

Community event participation and document review. The study team conducted a document review of data from multiple sources including Early Connections published reports, reports from partners (e.g. First 5 Alameda), and notes from community forums and community

and stakeholder advisory meetings. The explicit purpose of these meetings was to identify the driving factors impacting the SOC, and to prioritize actions that could address each issue. Any themes related to the two overarching research aims were included in the analysis.

Final Data Analysis and Interpretation

The totality of the data originating from the primary qualitative data collection methods, secondary quantitative data, and findings from the document review were compiled in order to identify the major overarching themes. The initial cumulative data analysis was conducted by two research assistants in collaboration with the field staff conducting interviews and focus groups; findings were reviewed by a data manager. A thematic analysis was conducted separately for the focus groups and key informant interviews, with attention paid to how often a theme arose, as well as the depth of data on a particular topic (Braun & Clarke, 2006). Codes and themes stayed close to the topic of inquiry, and were grounded in the key areas of focus, goals, and guiding principles of Early Connections. Disagreements between the two qualitative analysts were resolved through discussion; any discrepancies were resolved by the first author. After the internal study team reached consensus, the initial findings were then shared and discussed with the Needs Assessment Working Group. The Working Group identified common themes across data sources and patterns in responses. This resulted in the final overarching themes encompassing needs and strengths of families being served by the early childhood SOC.

Results

Themes are organized into two overarching categories which are aligned with the aforementioned aims. The first includes family needs and gaps in the SOC. The second includes family, provider, and system level strengths and opportunities that could be leveraged to improve the early childhood SOC. These themes emerged from the data collection and analysis and were prioritized by the research team, in conjunction with the Needs Assessment Working Group.

Qualitative and quantitative data are mixed in the results below, to provide a more robust picture of each theme. Sections with more qualitative data included represent the relative weight of data constituting that theme; thus some sections may have more qualitative data and/or data from different sources (i.e. parents or providers), while others are less robust. Similarly, quantitative data was included for each theme, where available. Absence of quantitative data in any theme indicates no relevant quantitative data were available.

Family Needs and System of Care Gaps

Family needs. *Unmet basic needs.* The highest need that families and providers identified were family's unmet basic needs including: lack of affordable child care/employment, housing, transportation (cost and time), and language barriers. From our quantitative data, many families reported living in unstable housing and in conditions of extreme poverty. All of children ages 0-5 served by the SOC received Medicaid services by definition, and over 85% of the families reported an income below \$25,000, which was insufficient to cover basic living expenses. Relatedly, one-third of caregivers were unemployed in the past 6 months. Almost half cited childcare problems as the primary contributing factor to unemployment. Among families receiving mental health services, single mothers were the most likely to have insufficient incomes.

Trauma and safety. Trauma and safety were identified as significant factors impacting the lives of young children with mental health needs, and their families. From our quantitative data, the majority of parents surveyed (70%) reported being highly stressed or exposed to trauma. Sources of trauma included domestic violence (40%), community violence (34%) and child abuse/neglect (28%). Parents in the focus groups elaborated on their concerns related to their children's exposure to violence: *"I'm always concerned for my children's emotional health because we live in such a violent community and our kids are getting killed."*

Clinicians were also concerned about the trauma many families experience. They spoke about parent's trauma, how that impacted the parent-child relationship and created attachment issues for the child, and the related challenges of the child's development and recovery process. They discussed how this impacted their work, and how they might address it:

“[We] need to understand the impact of trauma on families accessing services and to see if there are funding opportunities that promote flexible ways of working with families, not just looking at their symptoms, but at the things that are creating stress in their lives.”

System of Care needs. *Need for a family-driven approach.* Family members, providers, and other stakeholders felt that the early childhood services and system did not always put families first. Parents wanted services to respond to their unique cultural and linguistic needs. Some parents felt they were not heard by providers, and that the quality of communication could be improved. They expressed frustration that the system did not always value their lived experience, knowledge, and culture. One parent shared, *“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?”* Parents also reported needing more support and information about their child's development, including how to use evidence-based practices and interventions.

Care providers and Family Partners also expressed a need for a more family-centered approach. They recognized that while children are often impacted by untreated trauma, stress, or the mental health conditions of their parents, providers are unable to provide emotional support services for parents. Family partners wanted more professional development on child development and strategies for supporting parents of children with disabilities.

Fragmentation. Family members, providers, and other stakeholders reported that the system was fragmented, which resulted in children falling through the cracks. Multiple contributing factors to fragmentation were identified: participants reported major differences

across service providers and child-serving systems in assessments, language, funding, eligibility requirements, and understanding the availability and scope of different programs. This often led to the lack of a coordinated approach to comprehensive care for both children's mental health and their development, despite the strong link between them. Participants also discussed limited connection between the children's mental health system and the comparable adult system.

Participants attributed this fragmentation to a number of policy-level factors. Families discussed eligibility restrictions, Medi-Cal (California's Medicaid) coverage (which impacted the availability of preventative services), and limitations related to billing and documentation. Funding structures were a major contributing factor to service fragmentation. The separate funding streams of different agencies resulted in limited communication and collaboration between and across them. Service delivery was compartmentalized within an agency and rarely coordinated, which created duplicated efforts. Cross-agency collaboration was also rare and plans for treatment were often not shared. As one key stakeholder shared:

“I think we don't have a coordinated system, so we have a lot of different programs or services operating in isolation...families get bumped around from system to system; we should continually think, 'how can we make the system easier to navigate for parents and families?’”

Both parents and providers indicated a shortage of providers and programs, representing a serious contributing factor to system fragmentation. While the amount of screening has increased, providers indicated uncertainty around where to send families. Relatedly, a need was identified for advanced training for other professionals working with young children, such as early childhood teachers.

To remedy this system fragmentation, families indicated interest in a centralized hub, where all of their needs could be comprehensively met. Mental health providers emphasized the challenges to achieving this:

“Doing infrastructure (work) is not sexy. It’s not what people want to fund, it’s about fee for services. Until we start supporting some of those other things (collaboration, trainings, shared assessments), we’re not going to build a system of care that’s sustainable. It’s really that kind of investment!”

Provider accessibility and cultural responsiveness. While participants expressed a general concern about having enough providers and programs, a number of barriers to accessibility were also discussed by parents, providers, and other stakeholders. These include physical barriers to care, such as the location of services and insurance status, and linguistic and cultural barriers.

A number of these hard-to-reach populations were discussed, with providers and parents alike indicating concern about the availability and accessibility of care. In Alameda County, services are concentrated in one geographic area, posing a significant barrier to care, particularly for those with unmet transportation needs. Additionally, care providers often have long waiting lists, making it difficult for families to receive timely, responsive services.

Providers indicated concern about the accessibility of services for subgroups including the uninsured, foster families, and those with very young children. The need for early identification of social-emotional or behavioral issues in very young children was supported by the secondary data analysis. More than 60% of children served by the county mental health services were ages 3 and older. There was also concern about the availability of culturally-responsive and linguistically aligned providers, services, and support. This need was echoed by providers.

Early Childhood System Strengths and Opportunities

Parent/family. Despite the aforementioned personal and systemic barriers, providers acknowledged the incredible strength and resilience of parents and families caring for them. Mental health providers emphasized two key strengths of children and families that could be harnessed as opportunities to redesign the SOC: parental commitment and children's plasticity. Participants emphasized parents' commitment to, and investment in their children, discussing how every family, no matter what, is doing the best they can. As one provider explained, "*They are trying to be the best parent they can be for their child...and things get in the way, and we (services) fall through, but that's true for every parent that I've ever seen.*" Providers emphasized the importance of supporting children's inherent plasticity, mastery, and resilience to improve children's ability to build relationships, and develop their social and communication skills.

Provider. Provider strengths included a commitment to high-quality, family-driven, preventive care. Many clinicians and providers expressed deep care and concern about the families with whom they worked. They expressed a continued commitment to family-driven care, and were open to learning from, listening to, and supporting parents. Providers were also committed to early intervention and prevention. These strengths (i.e. commitment, care, and openness) could be harnessed to ensure the SOC continues to work towards the provision of high-quality, coordinated, and culturally responsive care, particularly for at-risk families.

System-level. Despite service fragmentation and availability, the needs assessment revealed a number of system-level strengths. The SOC underwent a number of transformations resulting in increased availability of services, the implementation of longer treatment plans, and the forming of organizational partnerships. Since 2003, ACBHCS partnered with 17 community-based mental health providers to serve the multidimensional needs of children ages 0-5 and their

families. Treatment plans expanded from 30 days to 60 days, and increased the number of children served. Additionally, a number of innovative partnerships were formed with schools and programs interfacing with young children, such as the Oakland Unified School District. Trainings were supported by First 5 Alameda County to enhance prevention and increase early intervention. These system transformations opened new opportunities for ongoing, multi-sector collaboration; this coordinated and integrated approach may have far-reaching benefits for the at-risk families served by the SOC.

Discussion

Our findings from Alameda County illuminate many of the challenges that racially, ethnically, and linguistically diverse families face in caring for their young children (age zero to five) with social-emotional or behavioral issues. This process recognized that children are nested in families, in communities, and in structures and organizations shaped by policies, and that all of these levels must be considered in a system of care. High-quality SOCs tackle multiple levels of health determinants simultaneously, taking an integrated approach to care. They can provide wrap-around services from multi-disciplinary professionals in a collaborative model, which not only better integrates care, but also delivers services without posing additional impediments to receiving care on already over-taxed families (King, Strachan, Tucker, Duwyn, & Shillington, 2009). Integrated care, delivered in a culturally responsive, coordinated manner is particularly important for young children, as this represents a critical period of development and an opportunity to positively impact the growth and development of at-risk children across their life course (Black et al., 2017).

Further, when a parent cannot meet their own basic immediate needs, it is exceedingly difficult for them to provide their young child(ren) with the optimal support needed for their growth and development, even when families also have substantial strengths. The stress that

families experience in working to meet their basic needs while also caring for their children often results in caregiver strain. This can lead to a negative cycle whereby caregiver strain negatively impacts their mental health and their ability to sustain employment, which in turn limits their ability to meet their family's basic needs (Brannan, Brannan, Sellmaier, & Rosenzweig, 2018). Understanding and documenting these connections between a family's trauma, safety, and unmet basic needs and their ability to support their young child's mental, emotional, and behavioral needs, provides an evidentiary foundation from which we can begin redesigning the SOC to be more responsive and effective.

Our findings, though restricted to a single geographic area and a single age range (children zero to five), reflect a broader need, recognized by families, providers, and organizations alike, to shift care delivery to be more responsive to the lived realities of young children and families (MacKean, Spragins, L'Heureux, Popp, Wikes, & Lipton, 2012). Such a SOC would be family-driven, culturally and linguistically responsive and accessible, and cohesive. This echoes national calls for an integrated SOC for the mental health and development of young children (Miller, Blau, Christopher & Jordan, 2012; Osofsky & Lieberman, 2011). Family-driven care is associated with early identification of social-emotional issues, caregiver empowerment, and decreased externalizing behaviors in young children (Graves & Shelton, 2007; Reijneveld, Hielkema, Stewart, & de Winter, 2017; Spencer, Blau & Mallery, 2010).

Despite acknowledging the need for, and importance of, a more cohesive model of care, those working within the system identified a number of impediments to actualizing this vision. While they prioritized and valued the family's lived experiences, they had neither the flexibility nor the capacity to expand their scope of practice beyond that individual child's immediate mental or behavioral health needs. This is in part due to a need for more training in delivering

family-centered care, as well as the recognition of systemic challenges such as isolated funding streams and few incentives for cross-institutional or cross-sector collaboration. These challenges are not necessarily limited to the SOC in Alameda County; they are shared by those working towards delivering family-centered care across the United States and beyond (MacKean, Spragins, L'Heureux, Popp, Wikes, & Lipton, 2012).

Study Strengths and Limitations

Using a participatory process, culturally- and linguistically-appropriate methods, and multiple data sources, this study has several strengths that help build the knowledge base about assets and needs related to SOC for families experiencing early childhood mental health issues.

One of the most notable strengths of our needs assessment was the use of a participatory process that incorporated the diverse perspectives of racial, ethnic, and linguistically representative families, and multiple key stakeholders in communities and within the SOC.

Across both qualitative and quantitative measures the study team worked to engage participants that were racially and ethnically diverse, to ensure findings were representative of the population being served. Additionally, the final themes were identified and prioritized in conjunction with the Needs Assessment Team. This ensured the key findings, and subsequent recommendations for improving the SOC, were grounded in the lived experiences of stakeholders.

Further, by leveraging primary data from qualitative methods, existing data from secondary sources, and notes and documents from community meetings and published reports, our findings were triangulated, to promote validity and reliability. Taken together, these findings, nested in the developmental ecological theoretical framework, resulted in a robust, stakeholder-grounded look at the experiences, needs, and strengths of parents and service providers in the SOC.

Nevertheless, limitations remain. Primarily, there are concerns about generalizability. First, we consider generalizability to all children zero to five with mental and behavioral health needs in Alameda County. There may have been selection bias if parents or families of children with multiple issues or greater severity may not have been able to leave their homes to participate. Additionally, participants were limited to those served by ACBHCS, who are lower-income than the general population. This also means people with no interaction with the system of care—but who may need such services—are excluded as well. Future researchers could randomly sample families and providers to more comprehensively understand the assets and needs of a community. Second, we can also consider generalizability beyond Alameda County. This is often a challenge for researchers doing community-based work. We argue that this research is more broadly generalizable in two main ways: Alameda County (and California more generally) are at the forefront of demographic shifts the U.S. is experiencing, and so these findings could be useful for promoting health and wellness in other municipalities (Hsu, Bryant, Hayes-Bautista, Partlow, & Hayes-Bautista, 2018). Second, we posit that some of the challenges these families faced are universal and are more reflective of their child’s health situation than their residential location.

Implications for Practice

The needs assessment findings have practice and system implications to inform planning and improvement of early childhood systems of care around the country. First, SOCs should serve the child’s whole family, by promoting family-driven care and connecting parents to employment opportunities, social services, play groups, recreational activities, and support groups. Second, SOCs can increase the scope of the system by better integrating early childhood mental health services and supports with other child- and parent-serving systems, and training providers and other front-line staff across the system (e.g., pediatricians, school staff, social

workers) on children's social-emotional and developmental needs. Third, it is important to consider those not yet in the system of care but who could benefit from being in it, to improve access to information, resources, support groups and services for those hardest to reach. Fourth, we encourage other SOCs to conduct participatory needs assessments to gather additional local insights to inform their own work. These can guide strategic planning efforts, help inform the development or modification of programs and systems, and support resource allocation decision-making, towards the larger goal of best meeting the needs of young children and families.

Implications for Future Research

Despite resounding calls for greater evidence and efforts focused on early childhood, there continues to be a dearth of studies regarding the unique needs of young children 0-5 with social emotional or behavioral concerns, and their families. We recommend that future researchers develop and study assessment tools that capture both the needs and strengths of families seeking early childhood mental and behavioral health services. Providers and government agencies must increase their understanding of family stressors and trauma, including how to best support the parents and caregivers of young children. Future research must also focus on the needs and strengths of service providers, including those providing direct mental health services, and those who could aid in early identification. Stakeholders engaged in this assessment process emphasized a local need that is also national: the shortage of mental health providers who can provide culturally responsive, developmentally-appropriate care (Bremmond & Weston, 2012). More system-level measures and tools must also be developed to capture the complexity of changing organizational structures and needs.

Conclusion

Providing high-quality, culturally responsive care is a priority of those working in the field of early childhood mental and behavioral health. Early Connections has been working

collaboratively with SOC stakeholders to identify the needs of diverse populations in California's Alameda County, and to identify and implement targeted strategies to address them. By grounding this work in the developmental ecological framework, the findings indicate a need for multi-level approaches to redesign the systems of care in order to support children as they are nested within families, communities, organizations, and the policy realm. This work contributes to the body of knowledge demonstrating the strengths of children and families, as well as the depth and breadth of their unmet needs.

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