Redesigning Behavioral Health Systems & Supports for Families

Parent Voices Final Report to the California Department of Health & Human Services

February 2023

Acknowledgements

Parent Voices and Social Policy Research Associates (SPR) would like to express our gratitude to the 27 parents who met with us to share their stories and experiences during the listening sessions.

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Introduction

The California Health and Human Services Agency (CalHHS) launched the [Children and Youth Behavioral Health Initiative (CYBHI)](#) in July 2021 to "enhance, expand and redesign the systems that support behavioral health for children and youth." The goal of CYBHI is to "reimagine mental health and emotional well-being for all children, youth, and families in California by delivering equitable, appropriate, timely and accessible behavioral health services and supports." In seeking to design and implement this initiative in partnership with community partners and stakeholders, CalHHS sought the support of Parent Voices to elevate the voices and experiences of California families.

Parent Voices led an effort to gain a deeper understanding of families' perspectives related to their children's ability to access quality behavioral health services. Parent Voices, in partnership with Social Policy Research Associates (SPR), held three listening sessions with families that covered topics related to CYBHI's goals and key outcomes, which are:

- **CYBHI Outcome #1:** Eliminate stigma related to behavioral health conditions and normalize help-seeking and wellness as part of everyday life.
- **CYBHI Outcome #2:** Embed preventive interventions and supports throughout the ecosystem to decrease downstream needs; and provide children and youth access to preventative mental health care and supports.
- **CYBHI Outcome #3:** Improve accessibility of services and supports, across the continuum of care, by building capacity and expanding the breadth of services.
- **CYBHI Outcome #4**: Equitably improve behavioral health outcomes across the state, addressing the needs of at-risk and underserved communities.
- **CYBHI Outcome #5:** Improve overall health, social outcomes, and emotional well-being for children and youth.
- **CYBHI Outcome #6:** Ensure that positive outcomes are sustainable in the short and long term.

This report summarizes the key themes and recommendations that parents shared across all three listening sessions. It begins by highlighting parents' perspectives on mental health and the mental health system, including how their ideal system would operate, the positive experiences they have had, and the challenges they have faced. It then summarizes the additional supports that parents want so that they can be better equipped to attend to mental health needs and provides a series of recommendations aimed at improving access to mental health support and services. Lastly, the report concludes with parents' overarching perspectives on mental health and the mental health system. Combined, these parent perspectives are intended to guide CalHHS and its relevant departments – namely, the California Department of Public Health (CDPH) – on efforts related to the CYBHI.

About the Parent Listening Sessions

Parent Voices organized three listening sessions with parents who reside in California and who are members of their chapters,[1] which were conducted between December 2022 and January 2023. Details about each listening session are described as follows:

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[1] Parent Voices has chapters in Alameda-Oakland, Contra Costa, Fresno, Marin, San Diego, San Francisco, San Joaquin, San Mateo, Solano, and Sonoma (https://www.parentvoices.org/chapters/)

- **Oakland Families**: Ten parents participated in this listening session, which was held in-person on a weekday evening in downtown Oakland. They described themselves as mothers, guardians, grandparents, current or former foster care parents, and child care providers, who have or care for one to eight children as young as two and as old as 19. All participants identified as Black women.[2] Parent Voices Oakland's program director convened the listening session and welcomed everyone. From there, SPR guided the conversation amongst parents.
- **Spanish Speaking Families**: Thirteen parents participated in this listening session, which was held virtually on a weekday evening. Among the parent participants, there were eight mothers and one father. Given the varying levels of English proficiency, this listening session was conducted in Spanish and facilitated by a Parent Voices staff member.
- **Virtual**: Four parents participated in this listening session, which was held virtually on a weekday evening. Parents had children as young as two and as old as 12. Parent Voices' organizing director convened the listening session and facilitated introductions. From there, SPR guided the conversation amongst parents.

Summaries of key themes and recommendations were drafted for each listening session (see Appendix for the individual listening session summaries). The following sections highlight key themes that were heard across all listening sessions.

Perspectives on Mental Health

This section highlights how parents/caregivers define mental health and key contributors to positive mental health. Overall, parents/caregivers shared that mental health is a critical aspect to a person's ability to thrive and affects everyone, regardless of race, age, gender, or other background characteristics. Their reflections around the key characteristics and defining qualities of mental health set the context for the themes and recommendations shared throughout the rest of this report.

Defining Qualities of Mental Health

Parents'/caregivers' discussion of mental health surfaced a set of defining qualities that explain what mental health means to parents and how mental health shows up in day-to-day life. These key qualities are explained below.

Mental health is reflected in a person's feelings, emotions, and thoughts and behaviors. Specifically, parents/caregivers shared that when a person's mental health is challenged, this may manifest in depression, anxiety, behavior, and eating disorders.

The ability to develop positive relationships and social interactions are defining qualities of mental health. Parents/caregivers described how mental health includes the extent to which a person feels comfortable managing relationships across contexts, noting that people who are facing a mental health challenge might feel held back from engaging in certain settings and unable to manage their life. This includes the ability to rely on other people for support and guidance during challenging times.

Mental health means having self-awareness and balance. Parents/caregivers shared that being mentally healthy means a person is stable, anchored, and able to think clearly through difficult times.

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[2] "Black" refers to descendants of people from the African diaspora, including but not limited to African Americans.

Moreover, parents/caregivers described the importance of being self-aware and having the ability to work through stress as key qualities of mental health.

Physical health is closely related to mental health. Some parents/caregivers shared the importance of balancing emotional well-being with physical health. They shared that physical activities were a positive outlet that helped their child regulate their energy and socialize in non-academic spaces.

Key Contributors to Positive Mental Health

In addition to sharing the key qualities that define mental health (as described above), parents/caregivers identified various contributors to a person's positive mental health. These contributors are explained in the following list.

Practicing self-care can support one's mental health. As an example, one parent/caregiver noted that they are taking on several responsibilities after the recent passing of their brother. Thus, the need for self-care was top-of-mind for this parent/caregiver, and they highlighted how self-care can not only help an individual's mental health but also the well-being of the greater community.

A child's upbringing and environment can impact their mental health later in life. Parents/caregivers shared how creating a supportive environment for children when they are young can set them up to have the tools they need to address mental health challenges later in life. For example, one parent/caregiver shared that she has helped her son by having him write in a journal every day.

Access to services impacts a child's ability to address any mental health challenges. Specifically, parents/caregivers noted that a child's mental health is impacted by any challenges or obstacles that can affect their learning. As such, the social, emotional, psychological, and behavioral services that children have access to directly impact their ability to address mental health challenges.

Family history can influence one's mental health. For example, one parent/caregiver shared that her family suffers from depression and mental illness. They highlighted that family history and experience with mental health can directly impact a person's own mental health journey.

A person's support systems contribute to positive mental health. Parents/caregivers shared that a person's support network and their ability to utilize that support network influences their mental health. Having a strong support system can help one's mental health.

> *"To me, mental health is having a support system, having people around me that can help me when I need help and knowing where to get help because not always can you do things alone. I think as women, we try to take everything on ourselves, at least, I think. So, for me that's what it is, having a good support system is good mental health for me."*

Parents'/caregivers' perceptions of mental health reflect the complexity and diversity of needs within the mental health system. With these defining qualities and contributors as context, the proceeding section elaborates on how parents/caregiver would like to experience the mental health system.

Ideal Vision of Mental Health & the Mental Health System

One of the goals of CYBHI is to "reimagine mental health and emotional well-being for all children, youth, and families in California." As part of this process, parents/caregivers shared their reflections on what their ideal vision of the mental health system looks like. Overall, their ideal mental health system works in tandem with other systems, has more trained personnel, provides resources and information to the community, and mitigates or eliminates the factors that contribute to mental health issues. These key themes are summarized below.

Vision for Ideal Mental Health System

Parents/caregivers described their ideal mental health system with the following qualities:

The mental health system works in cohesion with other sectors, such as education and medicine, to streamline communication and maximize support. Parents/caregivers want systems to speak more directly with one another to share key information and align in their approach to support a child and family in need of mental health services. For example, they want medical providers and schools to work together to support children's mental health. Ideally, medical providers would coordinate with schools to ensure that they are up to date on the assessments needed to diagnose children and can seamlessly transfer diagnoses across systems.

"Something ideal for me would be—I always wonder why systems don't work in coordination with one another. Sometimes the clinic says one thing, and the school says something else. Sometimes organizations offer you something completely different or it's a totally different system, and they don't coordinate with one another, at least where I live."

The mental health system has sufficient, qualified therapists and staff, some of whom are situated in schools to meet the demand of mental health services. Parents/caregivers want trained therapists to provide longer sessions for children to build trusting relationships with them. Additionally, parents/caregivers believe that the PreK-12 education system needs mental health coaches and socio-emotional learning (SEL) therapists to support students within school buildings, support teachers with academic and behavioral needs, provide referrals to external resources and organizations, and monitor students' development, similar to how the Women, Infants and Children (WIC) program monitors the development of babies and shares milestones with parents. Parents/caregivers shared that this WIC monitoring was helpful and should be carried into a PreK/elementary school setting, as it may help catch symptoms of autism or other behavioral issues.

"I would want for there to be a mental health coach or maybe even a life coach type of person at the school for kids that kind of guides them, a guidance counselor, I guess. And on an emotional level, I know they have counselors there, but I don't know it's like, they don't focus on the important things, I guess. They say they're there, but they're not able to even talk to the kids on that level because they're not either qualified or something or they don't have the funding. So, it's like what are they even there for?"

The mental health system is robust enough to address the many factors that cause or exacerbate mental health issues and illnesses among children and youth. Parents/caregivers understand that children are influenced by family dynamics (growing up in single-parent households), interactions in school (bullying), messages they internalize about societal expectations (beauty standards, shaming of disabilities, classism, racism), and external conditions related to their neighborhood (incarceration rates, alcohol and drug use). They believe that these and other factors need to be mitigated or eliminated in order to attend to mental health issues.

In addition to their ideal mental health system, parents/caregivers shared their ideal vision for how the community can promote better mental health, which is further described in the following section.

Vision for Community-Supported Mental Health

Parents/caregivers reflected on how community beliefs and actions related to mental health impact families and children, particularly given the misconceptions related to mental health issues. During the listening sessions, they shared their vision for a community that prioritizes children's mental health and approaches it with a more holistic and inclusive lens. Elements of this vision included:

Communities are united around wanting to support the mental health and well-being of children and families and are trained to recognize and respond to mental health needs. Parents/caregivers highlighted that there is "power in numbers [among] mothers that support each other," which can increase the likelihood for trust, rapport, and peer-to-peer support among families experiencing mental health challenges. Mental health issues not only arise at home and in school but can also occur through interactions in other places (grocery stores, extracurricular events, public spaces, etc.). As such, parents/caregivers want the community to be informed about different kinds of mental health needs and support strategies, which can combat mental health stigmas and serve as a starting point toward building a more supportive community that is mindful of and effectively responsive to mental health needs. More specifically, parents/caregivers want access to community parenting classes, so they have strategies for supporting their child's mental health.

> *"We all sometimes have something similar that we're struggling with. When it comes to the community, I think there has to be more unity…When my mom passed away, I found a lot of support in my friends and my family coming together... The night she passed away, a friend of mine took my three-year-old because I was crying so much and he [my three-year-old] had never stayed anywhere, he slept on top of her. Just little things like that, the trust and building that rapport with your friends, your family, the teachers, the school, the staff, getting involved… That's my ideal community where people aren't like, 'That's your problem.'"*
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> *"We need to start building the community's awareness so they can identify that a child has special needs. Sometimes parents will talk about how a child is bratty or spoiled or something else, but they don't know if that child might have autism or another condition. It's not just about informing families but also the community, because at the end of the day these children are all part of the community."*

Communities understand that children are still developing in their behavioral and social skills. Parents/caregivers highlighted that young children learn how to interact with others and communicate

effectively as they grow and mature. Currently, some parents/caregivers feel that the community expects children to already know how to communicate and act across a variety of situations. These expectations do not set children up for success, and therefore parents/caregivers hope that the community will someday embrace the developmental phases of a child and not expect them to act like an adult when they are only children.

"They're being hard on kids [and] expect them to not cry or to not throw a tantrum or to not have fits or not like something or tell you no. But it's like, as adults, we're trying to learn how to do that still or set boundaries and things like that. I think it comes from we were raised that way because nobody knew. But it's like we could have more conversations and [raise awareness about understanding and expressing emotions and setting boundaries]. It could help change it. Just respecting kids' mental health and respecting them as people. And just because they're little kids doesn't mean they don't have feelings, or they don't think for themselves. It's just taking the time to listen and stuff and just take care of them. Be a little more compassionate. Then they feel comfortable to just be themselves and make their own decisions."

The community has safe spaces for children and youth to gather and play. Parents/caregivers agreed that it was important to have community spaces such as teen groups or community center gatherings where youth can come together and learn from one another. Some stated that their children needed more physical spaces to play, since current activities are not financially accessible to families and open spaces (e.g., parks) are not always safe. Having these community resources would signal that the community prioritizes mental health.

"Right now, there are not that many places that are economically accessible to families, where children can have some physical activity. It's proven that children, humans in general, who have more physical activity and more contact with nature are less exposed to emotional imbalances. But this is not accessible to families with fewer resources. For example, paying for soccer for my children is $300-$500, my daughter's gymnastics class is almost $400 per month. If they don't have somewhere to channel their energy, they will not be as balanced."

Communities mitigate gendered expectations and norms within families to increase a father's involvement in their child's mental health. Most of the families in the Spanish language focus group came from cultures that reinforce traditional gender norms, wherein the husband is head of household and breadwinner while the wife attends to household responsibilities and the children. This sense of machismo also reinforces the notion that a man should not show emotion, leaving the emotional labor to a woman. One mother discussed how, at first, she was the primary parent seeking support and attending to their child's mental health needs, while her husband continued working with minimal involvement in their child's situation. To her satisfaction, over time, her husband became more involved in their child's needs. There is an opportunity to engage all family members when thinking about mental health outreach and education.

"I sometimes wish he [husband] was more involved. It's as if the man is predisposed to be the head of household and be the provider, which leaves the child care and anything having to do with the children to the woman. In other situations that don't have to do with our children, I've noticed that it's difficult for men to take on the initiative to be more involved with the doctors or attend appointments, like IEPs. In that sense, I think my husband has matured and changed a lot. He asks for permission at work to attend my son's appointments. He used to think that no one would understand or respect his decision to not go to work to be with his son and wife at appointments."

The community honors and celebrates differences among families and children. Parents/caregivers shared how it is important for people to be aware that while some children have disabilities, they simultaneously have great abilities. Thus, parents/caregivers would like the community to approach all children through an asset-based lens so that all children feel comfortable and can more easily thrive in their environments.

Positive Experiences with the Mental Health System

While many parents/caregivers shared that they have felt successful with addressing mental health challenges on their own (i.e., creating safe spaces for their children to share their emotions, reaching out for support from family members) some have also benefited from positive interactions with the mental health system. Namely, parents/caregivers complimented certain features of the mental health system and highlighted experiences with mental health professionals that felt supportive and helpful. These examples are detailed below.

Online platforms for behavioral health offered through medical clinics have been useful. For example, one parent/caregiver shared that her family doctor provided them with a behavioral health online platform to check in about her children's mental health. This platform and referrals through the platform have been a positive experience for that parent/caregiver.

Some children were able to access supports and services that have improved their mental health and well-being. Namely, interactions with therapists and school staff were shared as positive examples, including:

- A few parents/caregivers shared stories about how school staff noticed behaviors in their child, which was often an initial and important sign to seek appropriate services for their children.
- Additionally, some parents/caregivers noted that they had contacted school staff to help fill out medical forms. School staff then shared their observations on the forms, which helped parents/caregivers secure an evaluation with their medical provider to determine whether their child had a certain diagnosis.
- Some parents/caregivers spoke about positive interactions with therapists who supported their child, informed parents/caregivers of behaviors to monitor, and equipped parents/caregivers with strategies and tools to continue focusing on their child's well-being outside of therapy sessions.

> *"It's been a long process, but it's been satisfying because I've seen how much my child has progressed. I've seen how he's improved, how all the advice and suggestions that the counselor has given me I've tried to carry out, and there are some that don't work for us, but the majority do. I've noticed that he's had like anxiety attacks, and that he directs his anxiety towards his hands. He's asked me for a deck of cards, which he will shuffle, or rubber bands or other simple things that help him [calm his anxiety by attending to his fidgety hands] and relax him a lot. Personally, I think that having the counselor has been very helpful."*

Parents/caregivers have been able to access services and interact productively with health care professionals to support their own health and that of their family. Some parents/caregivers were able to receive supportive health care, resources, and advice to help them as individuals and parents/caregivers. Specific examples include:

- One parent/caregiver explained how she gave birth to twins and had specific mental health needs following this birth. She felt that her needs were generally met by the mental health system that supported her postpartum.
- One parent/caregiver shared about an instance where a doctor explained what was happening inside her child's brain when he was on social media. The doctor went on to explain the science behind mental health in a way that resonated for this parent/caregiver.
- Another parent/caregiver shared that their doctor explained that their Medi-Cal insurance would be turned down by most services providers. The doctor then recommended they switch to the other Medi-Cal insurance as soon as possible because they will have a much easier time scheduling.
- Lastly, a parent/caregiver shared that a hospital staff member explained that parents/caregivers can apply for grants if their child has a medical need for therapy, but the family does not have enough money. This parent/caregiver is now, after months of searching for a therapist, being connected to someone who can help her apply for grants to cover the costs.

While this section highlighted ways in which some aspects of the mental health system have worked for parents/caregivers, the proceeding section explores opportunities to expand these positive experiences given the mental health challenges parents/caregivers have faced.

Challenges with Mental Health & the Mental Health System

Parents/caregivers highlighted personal challenges with mental health for themselves, their children, and other family members. They also identified external challenges they faced when navigating various systems when seeking support. These challenges are elaborated on below.

Personal Challenges with Mental Health

Parents/caregivers shared that they face challenges related to addressing and communicating about mental health in their families. Parents/caregivers also shared personal struggles with mental health from their past. Below is a summary of these challenges.

Children are still in dire need of mental health services after the pandemic. Parents/caregivers described how shutting down schools during the COVID-19 pandemic has affected children and youth's

mental health. One parent/caregiver shared that her own daughter suffers from post-traumatic depression because of the pandemic. Another parent/caregiver noted that it seems like people expect them to continue as if they're okay.

Youth and children often find it challenging to discuss mental health and share their needs. Many parents/caregivers noticed that their child has a difficult time sharing about their hardships. Parents/caregivers described instances when their child waited for weeks or months before speaking up about challenges they experienced. Some parents/caregivers note that this is because children do not understand how they feel, so they are unable to communicate their emotions. Other parents/caregivers shared that they believe their children might have internalized misconceptions of mental health, which also exists within their community. Moreover, parents/caregivers shared that their children have difficulty communicating what mental health supports they need. In response, parents/caregivers try to be patient, "meet them at their level," and encourage their children to feel and express their emotions appropriately.

> *"I think it's hard [for a child] to call it by its name. And its name is mental health. There's stigma [associated] with that word. But talking about emotions, about how to manage them, and what they [the child] is living through [is okay]. I agree with the idea that when a parent sees a change in their attitude it's a red flag that something is going on."*

Bullying is a major mental health issue affecting children and youth. As noted previously, parents/caregivers identified bullying as a factor that causes and exacerbates mental health issues for their children. Several parents/caregivers shared that their children are experiencing bullying and that this often takes place in school. Some parents/caregivers noted that they found out through teachers and friends that their child was being bullied, rather than hearing it from their child.

Negative stigmas associated with mental health create barriers for those in need of support. Parents/caregivers noted that mental health is often misunderstood and avoided in their communities, as it is considered a taboo topic. People with mental health issues are often labeled "crazy" which can then lead to them feeling ashamed and not seeking support or sharing about their challenges. One parent/caregiver shared that her family gave her a "complex" from calling her "crazy" because she was born in a jail and both her birth parents were addicted to drugs. Parents/caregivers also shared that they have had difficulty talking to family members with mental illness about how to support them; family members were often unreceptive to conversation and grew angry or frustrated.

> *"My 14-year-old son has a therapist. I saw that he was a bit anxious, and I thought he was a bit depressed. When I suggested the idea of going to therapy, he was 10 years old and the first thing he told me was, 'I'm not crazy.' There is a stigma, as if talking about mental health is like saying you're crazy, which is wrong. It's been a long process, but I've seen how much he's advanced."*

Challenges with the Mental Health System

In addition to their more personal challenges, parents/caregivers also shared specific challenges they have experienced within the mental health system. Parents/caregivers described having difficulty finding and receiving quality care, as well as specific issues with their local school systems. These

challenges are described below and organized into three categories, 1) mental health care, 2) general health care, and 3) education.

Mental Health Care

Parents/caregivers are having difficulty finding a therapist, especially one who meets their children's needs. Parents/caregivers described long, arduous searches for therapy services where they are being turned away because therapists want more money, do not take their insurance, or do not work with younger children. For some who are able to find a therapist, they noted that some therapists would only offer sessions over the phone or on a virtual platform without turning on their camera. Parents/caregivers felt that these therapists were not trying to develop a bond or engage with their children. Parents/caregivers described this lack of effort as unprofessional, unproductive, and ineffective.

"She's telling me, Gram Gram, I need to see a therapist. Come on. I keep trying to get her a therapist. The therapist is going for more money. They're opting out."

"I've faced many barriers for my children, especially during COVID. My child's emotional stability was very affected. I sought help for my son, and I was so frustrated when a so-called therapist offered a Zoom session but didn't even turn on their camera. They didn't even try to connect with my son. Sometimes the session was over the phone. I thought, 'Really?' You're trying to teach my son about managing his emotions, about how to do things, but you're not even trying to connect with him and understand his emotions, which I think is very important."

"I'm not sure if this person or the therapist does want to work harder or this is not her field or it's just very overwhelming for her. It's just very difficult to have this kind of understanding and communication when it comes to therapy. And that's why I ended up not having any therapy for him because I just felt like she doesn't understand him, and she doesn't understand what I'm talking about. It's been very difficult. So, this is very ... For me, it's very important to find the right person when you communicate, and they understand what you're talking about."

Insurance limitations and therapists' decisions to "graduate" clients are impeding children's continuity of care. Parents/caregivers shared their frustration upon learning that their child needed to switch therapists, often because they reached their allotted sessions. This shift often happened when the child was developing trust with their therapist, resulting in a major setback in needing to build rapport with a new therapist. Additionally, some parents/caregivers believed that their child was "graduated" too early from their sessions, as their children often "relapsed" and repeated problematic behaviors after ending therapy.

"My child's therapist has been changed. The contract with the services and with that therapist ends and they assign you a different one. And my son is barely starting to open up and trust when they inform him that they will not have the same therapist in the next few weeks. And that means needing to start from zero again. It's difficult for my children to open up and develop a sense of trust to then be notified that they'll be working with someone else."

"They [therapists] set their sessions with goals, and when the child has met some of those goals the therapists 'graduates' them. They say, 'We met your goals. You don't need to continue attending' and they just let them be. And guess what happens? I've seen it with my son. He was 'graduated' twice from his sessions, and 2-3 months later he falls back to the same habits as if he hadn't been in therapy. He needs to have continuous support and not to be told 'You reached your goal, goodbye.' Because then we have to start all over again – we have to apply again and wait our turn on the waiting list until another kid is 'graduated.'"

There is a shortage of therapists to meet the demand for mental health services. Some parents/caregivers spoke about their experiences being on long waiting lists for their children to begin therapy. Parents/caregivers noted that the current pool of therapists is trying to meet a high demand as best as they can, however, due to large client loads, their children's sessions are shortened. This results in children not getting the time they need to develop trust and open up to their therapist.

"I think that the services that are provided are limited. There is so much need for so many children that there are not enough therapists and psychologists, so you are put on an almost infinite waiting list whether that be at school or external services."

It is challenging for parents/caregivers to access appropriate behavioral health assessments for their children. One parent/caregiver shared that she wanted to re-evaluate her child as she thought the first diagnosis was incorrect. However, the process was convoluted and inaccessible, resulting in her child not being able to receive a re-evaluation.

"I really wanted to re-evaluate my child, because I don't feel like he's struggling with the same diagnosis as when they diagnosed him at the age of two. We didn't get a chance to do this, because the UCSF [University of California San Francisco] or any other places that you can do that, they always had this long waiting list to do this. To be honest, [the doctor] talked to the health professional, and they also talked to the social worker, and they explained to them my needs and everything, and the reason why I need to do this. They do things, but they did them very slowly, and sometimes they forgot about them, and I have to remind them many times. You know, 'This is what I need, and we need to do it as soon as possible.'"

General Health Care

Parents/caregivers must put in a lot of work to navigate the health care system and secure services. Parents/caregivers are forced to talk to many different people to find and access services. When parents/caregivers go to their doctor or call 211, they are referred repeatedly to other organizations or entities. When the typical process for receiving services fails them, parents/caregivers described being forced to do their own research to find services and support. Parents/caregivers would call and email many people to advocate for themselves and their children, often resorting to identifying staff in positions of power and pleading for their help.

"…almost anywhere you go, it's always 'go to this person and go to that person,' and that person is sending you back to the same person."

"Well, I kept doing emails and like [another focus group participant] said at the end of the table, you have to go above someone's supervisor. You just have to keep climbing the ladder and advocating for yourself and your children. And so, I had to do a lot of advocating, a lot of it."

To navigate healthcare systems, parents/caregivers must often rely on insider tricks from their personal contacts. Parents/caregivers described getting advice and receiving resources and information from other parents, rather than from health care professionals and staff. Thus, getting information on how to receive services is often dependent upon who they know and whether their connections have the knowledge they need. For example, a parent/caregiver described learning medical terminology from a connection that helped her better advocate for herself.

"So, there's certain terminology you need to learn to use too, when you're talking to people, because it lets them know... it's sad how this world is run, but it's the truth."

Insurance challenges pose a major barrier for receiving services. Parents/caregivers noted that service providers are not sensitive to their financial situations, asking them to pay out-of-pocket and be reimbursed by insurance; however, this is not always an option for families with lower incomes. Parents/caregivers also discussed barriers they faced with Medi-Cal insurance. Specifically, families struggle deciding which Medi-Cal insurance (Alameda Alliance and Blue Cross) is the best option for their family's needs. It was also noted that not everyone is aware that they even have the option to choose.

A family's geographic location impacts their ability to receive services. Parents/caregivers noted that some cities allocate more money to certain health services and resources, so residents of those cities have access to better care. Additionally, it was noted that sometimes these more-resourced cities can be very exclusionary.

"People don't want you to come to their city if you don't live there…They don't want to share their resources...They don't want outside people coming in."

Education

Schools are not properly staffed or trained to support students' mental health. Parents/caregivers noted that there are not enough supportive staff, such as counselors or specialists, in schools to meet the students' needs. The ratio of counselor to student is too high, thus counselors often have large caseloads which limit their capacity to give students individualized attention. Moreover, the lack of personnel has come to affect communication among staff, as parents/caregivers described sharing their children's conditions or needs with administrators who then failed to communicate with staff that frequently interacted with their children.

The education system is not a reliable place to receive support. Parents/caregivers noted that school staff are not approaching children's mental health comprehensively, helping connect families to resources, nor prioritizing health care professionals' requests of them. Moreover, parents/caregivers noted that school systems currently do not support their children with their most basic needs. Given this perception of school inadequacy, parents/caregivers were unsure if schools had the capacity to take on any additional mental health supports. One parent/caregiver shared that their local school district is more focused on politics and interested in money than caring for students.

"When I've asked for emotional support for my son, so he can control his emotions in school settings, I'm told, 'Yes, we have someone who can help,' but the school isn't specific in saying, 'We're going to give you an appointment and this is the program or steps we're going to take, or this is what we're working on together.' They only give you surface-level information, but there is no system that works together with families."

"When the psychologist sent some forms for the teachers at the high school to respond to, only one teacher filled them out. This was during COVID so there were other challenges, but there was no interest from the teachers to help resolve this. I suppose that it was a time when they had a lot of work, but unfortunately this request was coming from the psychologist, and they didn't prioritize it because they had other things going on with distance learning. So, my daughter doesn't go to therapy anymore, and I'm left with the doubt of what happened [and why they didn't fill out the forms]."

School staff often create barriers for parents/caregivers trying to access mental health services for their children. Parents/caregivers noted that some staff are not attentive to supporting families and students. Parents/caregivers described staff dismissing their concerns that their children need support when going through difficult times. Parents/caregivers felt that this was due to staffs' preconceived notions of what a child in crisis looks like. Staff have also refused to fill out documents that would allow children to be evaluated by their medical practitioner or specialist for mental health support.

"I recently lost my sister, and before that I lost my mother. I asked for my daughter to receive support for this grief. I noticed that she was depressed and confused about their passing. They [the school] never offered me support. They told me, 'Oh, she looks fine at school' but they never took the time to talk to her in private to ask her how she was doing."

"My son looks 'normal' and has a high academic performance. The principal removed some of the services he had, because she said that he was academically high-achieving and that because of his good grades he didn't need to be evaluated or seen or treated. I didn't feel supported by the principal."

The process to get an individualized education plan (IEP) is challenging. Parents/caregivers shared that the schools require a specific diagnosis to have a student qualify for an IEP. However, parents/caregivers interacted with doctors that were unwilling to sign off on the statement for an IEP; therefore, their children did not receive proper accommodations.

"For me, my son has been diagnosed autistic and ADHD, but the school denies him of the IEP. They say because he's too smart academically, that's the reason why they don't recommend him to have an IEP. But it's like, if I'm asking for it, the doctors all recommend him to have an IEP. How are they able to say that?"

Manifestations of Anti-Black Racism Impacting Mental Health

Black parents/caregivers participating in the Oakland Families listening session often described coming up against anti-Black racism when accessing services, as well as its impacts on their families' mental health and emotional well-being. As research has shown, "anti-Black racism has negatively contributed to the physical, emotional, psychological health and well-being of Black people."[2] They shared several experiences where health care staff and professionals racially discriminated against them, which highlighted the interpersonal racism that they faced in the mental health system. It was noted that people of all races have pre-conceived notions about Black people and often profile them, however, these experiences occurred most often with white people.

One mother shared about the constant need to advocate for herself and her family while living in Berkeley. Her family was entitled to specific services as residents of the city; however, their residency was repeatedly called into question, and staff tried to deny them support.

"You have to fight for your children in Berkeley…Okay, if you live in Berkeley, first of all, first thing when you call or you're in, they've got to say, 'Do you live in Berkeley?' Especially if you're Black."

"When you say you're coming from East Oakland. They will try to do everything possible to keep you out of services in Berkeley."

Another mother described experiences where staff would "treat [her] like garbage" and not listen to her because she was a Black woman with a history of drug use. In response to this, she would be upset and/or advocate for herself or her family, which staff would then interpret as anger.

"I broke down, and you know, the white people, they don't like your Black folk emotion. They don't know what to do with it. They don't honor it."

When identifying the challenges they faced and observed in their families' daily lives, parents/caregivers also described how institutional, systemic, and structural anti-Black racism affected their families' mental health, healing, and access to needed resources and supports. Parents/caregivers touched on how this negatively impacted their families' emotional well-being as well as their ability to thrive. Some examples include the oversexualization of Black girls and women, adultification of Black children and youth, the school-to-prison pipeline, criminalization and mass incarceration of Black and brown people, and anti-Black school curriculum.

"You will see the little Black boy outside of class and he's sitting down in the corner, and you see the teacher chastising him, and I said to him, 'Why every time I've got to go to this school to pick up my daughter, a Black boy is sitting out here in the hallway?' And it really disturbed my spirit because I had a small boy."

The Oakland parents'/caregivers' reflections and lived experiences lift up the dire need to acknowledge and dismantle anti-Black racism in the mental health system and beyond as part of any effort to reimagine mental health and emotional well-being for California's children, youth, and families and improve access to services and supports.

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[3] Williams Comrie et al. https://www.bu.edu/antiracism-center/files/2022/06/Anti-Black.pdf

This section highlighted the many challenges parents/caregivers and families face when addressing mental health needs and navigating systems to access resources and supports. Their lived experiences highlight the barriers that families routinely face when trying to support their families' well-being. The next section dives deeper into the specific mental health recommendations and supports that they've identified as priority.

Recommendations

Parents'/caregivers' perspectives and comments yielded a set of recommendations to improve the mental health system and support the CYBHI public health campaign. They have identified meaningful and impactful solutions to ensure that the mental health system is just, fair, and inclusive. These recommendations can be used as a starting point for reimagining mental health and emotional well-being for children, youth, and families in California.

Recommendations to Improve the Mental Health System

Based on their lived experiences, parents/caregivers shared recommendations to improve the mental health system. Their recommendations are described below and organized into two categories, 1) mental health care, and 2) education and community.

Mental Health Care

1. **Improve the accessibility and affordability of mental health services.** Services should be available to all families, but especially to people of color and those with low incomes. They should also be free of charge or offered at an affordable price. Moreover, a parent/caregiver noted that no one should be denied any health care services that may save their life.

"Even if you know about it, you might not get covered. Even if you know about it and ask for it, you might be denied. So, in that sense, when I'm thinking vision, what's your vision? Nobody is denied care that will help save their life."

2. **Invest in strengthening the number and quality of mental health professionals.** Parents/caregivers recommended additional training and/or pipeline programs to increase the number of therapists and counselors available to effectively support their children.
3. **Remove insurance and cost limitations to allow more frequent therapy visits for children and youth.** Parents/caregivers would like their children to see their therapist more regularly and frequently at a cost that they can afford.

4. **Reduce navigation challenges by providing a clear pathway to accessing and securing services.** Parents/caregivers "just need to know exactly where to go instead of having the run around," specifically as it relates to prevention and services. Parents/caregivers should have a clear path to accessing services and resources, thus removing the need for parents/caregivers to seek advice in their community or contact a specific person in the health care system. Additionally, when referred to another service provider, the original provider or support navigator should always confirm that the family has a scheduled appointment and received services.

5. **Provide educational mental health programming for parents.** Parents/caregivers would like to attend workshops and classes to learn about autism, IEPs, and other mental health topics including what mental health encompasses and how to talk about it with youth. Parents/caregivers see these workshops as an opportunity to identify strategies that they can practice at home to further promote mental health outside of therapy. The location and schedule of these offerings should be convenient for parents/caregivers to support attendance (e.g., at schools during parent-teacher conference week). These activities can support parents/caregivers with checking in on their children to listen to and care for their well-being.

6. **Children's mental health plans should include both emotional and physical strategies.** Parents/caregivers would like their children to engage in physical activities outside of counseling sessions. Parents/caregivers believe that maintaining an emotional and physical balance will better support their children.

7. **Improve accessibility to behavioral health assessments.** Parents/caregivers consistently shared challenges with getting the services and evaluations they needed to properly diagnose their child and receive an IEP (when needed). They suggested that these services become available at multiple community locations, other than hospitals, so that more families can access them.

Education and Community

8. **Equip schools to better support students and families' mental health.** Some parents/caregivers would like to see their local school system provide resources for students and help parents/caregivers better support their children with emotional challenges. They also

recommended trainings for teachers to enhance their communication skills around mental health and be better equipped to support their students. Parents/caregivers would like to see school staff focus their attention on supporting students' mental health when they are causing "trouble," rather than penalizing them.

"I have this experience myself with my child when we were one particular school, he has nothing, he has no support at all. And then when he took into another school, he's getting not only emotional support and everybody is aware of what he was expected to do, what are his strength, whereas where are his weaknesses, and I feel like it's very important to have all this support for the child to flourish and grow because if this is missing, nothing is functioning on this child. It's just everything is, it just feel falling apart still."

9. **In contrast to the bullet above, consider removing schools from the mental health system altogether.** Other parents/caregivers want their school to focus on "be[ing] a school" rather than trying to also support students' mental health. A parent/caregiver recommended that if anything happens to a child at school that is health or mental health related, a parent/caregiver should be notified, and the child should be taken to a professional.

10. **Hire more Black teachers and teachers of color.** As noted previously, children's mental health and well-being are being negatively impacted by numerous factors that occur in their schools. Parents/caregivers shared that having teachers of color will help improve health outcomes for their children because those teachers will be able to relate to children of colors' lived experiences. More specifically, some parents/caregivers felt that more Black male mentors are needed to interact with and guide young Black men. This is also important because children spend so much time at school and thus, they need teachers who come from similar cultures.

"If they [schools] have more people of color that can really resonate with you - you may have lived in the neighborhood, you may have lived in a building, you may have been to school, but it doesn't really quite resonate because the day-to-day life is different."

11. **Improve school climate to mitigate the bullying that children experience in the classroom.** Across all three listening sessions, parents shared that their child often experienced mental health issues on school grounds because of bullying. As such, they emphasized the need to address school climate – and the bullying that can come with a negative school climate – when thinking about improving the mental health system.
12. **School staff need their own mental health support.** A parent/caregiver noted that school staff have their own mental health issues that they need to address. When staff do not get the services they need, this negatively impacts the children with whom they interact.
13. **Support skilled and trusted community-based organizations to build connection amongst parents.** Parents/caregivers shared that going to parent/caregiver-focused events allows them to build community with one another, which is key to their own mental health and promoting that of others.

Recommendations for the CYBHI Campaign

Parents/caregivers provided specific recommendations for the Children and Youth Behavioral Health Initiative. These recommendations can assist CDPH as they design and implement the initiative in collaboration with community partners and stakeholders. Parents/caregivers recommendations are organized below into three categories, 1) CDPH decision making, 2) parent access, and 3) marketing to parents.

CDPH Decision Making

1. **Conduct a focus group with Black men.** During the Oakland Families listening session, parents/caregivers noted that there were no Black men present. They recommend that CDPH reach out to Black men to hear their perspectives and experiences related to mental health, particularly Black men who have experienced mental health issues and illness.

"What you [CDPH] need is some of these Black men at the table; some of these Black young men that's been gone through this. You understand what I'm saying? That has experienced this so that they can give you [CDPH] their story. We only telling our part of the story."

2. **Include Black men and women when making decisions.** Parents/caregivers from the Oakland Families listening session commented on the importance of having representation at tables of power. They recommended that CDPH ensure that Black men and women have input in any decision making, specifically how public funding will be used and where it will go.

Parent Access

3. **Utilize social media to reach parents and families.** CDPH should use social media platforms to share the CYBHI campaign. Tik Tok and Instagram were specifically identified as platforms that parents/caregivers use. Parents/caregivers shared that they already use these platforms to learn about mental health and would gladly "follow" CDPH and "like their posts" if they were to set up a social media account.

4. **Make information available at common community sites.** Parents/caregivers noted that not all families can be reached through social media, so it is important that the campaign employ other outreach methods as well. Parents/caregivers recommended sharing information and distributing flyers at community sites that they frequent, including schools, churches, clinics, grocery stores, gyms, and their workplaces. Additionally, television commercials would be beneficial. These forms of outreach are important because parents'/caregivers' access to the internet and reading levels vary.

"I think it's a good idea to use Facebook [or other social media platforms], but we should also remember that there are some parents who don't know how to use social media or the internet. There are also some parents who do not know how to read or write. So, I think that giving workshops or presentations in schools or churches would be good, that way they can hear and retain some of the information that is being shared."

5. **Consider employing parents to deliver content.** Parents/caregivers have existing networks with one another and often obtain information from people in their community. Thus, parents/caregivers recommended identifying and compensating a group of parents/caregivers to promote the campaign in their respective communities.

6. **Expand access to parents/caregivers outside of benefits systems.** A parent/caregiver noted that they received helpful information about mental health services when they applied to CalWORKs. This parent/caregiver suggested that all parents/caregivers receive these resources, not just those who are CalWORKs eligible.

Marketing to Parents

7. **Ensure content is meaningful to parents/caregivers.** Parents/caregivers shared specific content areas where they would like more information and on which they would like CDPH to focus their content. Parents/caregivers identified the following topics:
   - Mental health programs, including the science behind mental health
   - Drug and alcohol programs
   - Recognizing autism in children
   - Knowing the signs for behavioral challenges
   - Understanding how technology and social medial can influence mental health
   - Understanding how nutrition can impact mental health and behavior
   - Knowledge about how to cultivate emotional well-being at home

"So, each individual has a different set of behaviors or different things that affect them in their daily lives. And so, I think the unawareness and not knowing is a problem because then that creates... It makes it harder for those people dealing with it. So I think if people are more educated on things like that, how to spot those behaviors and what to do, how do you treat someone dealing with certain disabilities or different mental health issues if someone has ADHD, they'd be like, "Oh, that person has ADHD because they're doing this behaviors, I can know how to handle them at their level because I can notice it."

8. **Design content to grab parents'/caregivers' attention.** Parents/caregivers specifically recommended that content be messaged a specific way; first a relatable challenge should be identified (e.g., identifying behavior challenges in children) and then a specific resource(s) can be shared. Parents/caregivers noted that messaging content this way would help them feel less alone and would reduce negative stigma associated with mental health.

9. **Develop content and teacher training that honors the history and power of the Black community.** As described in the textbox above, many Black mothers experienced institutional, systemic, and structural anti-Black racism that impacted their and their children's mental health. They believe it is necessary to teach children about the African royalty from which they descend, so as to communicate who they are descendants of, what they and their ancestors have overcome, and how it is okay to access services that help them tap into their power and pride, particularly as they navigate the mental health system.

"We come from Kings and Queens… That little boy sitting outside the classroom, he doesn't know that, and that teacher is beating down his self-esteem and spirit."

Concluding Reflections

Overall, parents/caregivers stressed the importance of mental and emotional well-being for themselves and their children. They shared that with a strong mental health system and a community that embraces mental health, children will have improved behavioral development, higher confidence, more self-esteem, fewer experiences with bullying/teasing, and feel more empowered to stand up for themselves. Moreover, knowing that the resources in the community exist for all families (regardless of income or race/ethnicity) puts less stress on parents, supporting them to be better parents/caregivers to their children.

> *"If all of that was in place, I think my son's development would be a lot further along than it is right now. He would be a lot more confident in himself, and his self-esteem would be up, and be just encouraged to try to just want to be better, because he has a hard time with that. Being autistic, they have a lot of fears and anxiety and things that he's always afraid of just doing different things."*

Despite this opportunity to express their thoughts and feedback on how to improve the mental health system, some parents/caregivers feel that their needs will not be considered by those in power. Namely, the parents/caregivers participating in the Oakland Families listening session communicated feelings of hopelessness toward the end of the conversation; one parent/caregiver noted that they are often being asked about what they want, but nothing changes after.

> *"…they [the California Department of Public Health] want to know what we want, and we speak about what we want. It don't make no difference. Look how long we've been talking about it."*

This report has illustrated the strong and critical role that mental health and well-being play in supporting thriving families, including how anti-Black racism negatively impacts mental health and interactions with the mental health system. Additionally, this report shares parents'/caregivers' clear recommendations for addressing the many challenges that families currently face with the mental health system. Given parents'/caregivers' perceptions on the lack of prioritization of their views, as CHHS moves forward with CYBHI, it is imperative to keep parents'/caregivers' voices and recommendations at the forefront of implementation.