

State of the Community Executive Report

Cumulative 2017 – 2020

True to its vision and mission, Parents and Caregivers for Wellness (PC4W) over the past three years has provided direct outreach and engagement to parents and caregivers throughout California to support and equip them to manage the mental health needs of their children, even during the 2020 global pandemic. As a direct result, from 2017 – the Present, parents and caregivers have become more trauma-informed; have greater access to services and supports; enjoy a more holistic approach from providers; and are better able to help other parents and caregivers through peer-to-peer support.

With United Parents as the lead, PC4W has also had a decisive impact on organizations that support parents and caregivers, many of which are parent or caregiver led. As a direct result of PC4W's efforts and advocacy, these organizations have been able to maximize funding by expanding services to more parents and caregivers following PC4W's outreach and engagement. They now recognize PC4W as the conduit of mental health information between parents and caregivers and policy/decision makers throughout the state. Also, they have themselves done more to integrate the authentic voice of parents and caregivers into planning and governance.

From 2017 – the Present PC4W built capacity through the following:

- Annual State of the Community Reports
- Outreach and engagement to over 40,000 parents and

caregivers and to over 300 child- and family-serving organizations

- 948 participants in 13 regional training events, with additional participation at supplemental county training events
- 1,217 participants in statewide training events, including California Mental Health Advocates for Children and Youth (CMHACY) Conference, National Alliance on Mental Illness (NAMI) California Annual Conference, Leadership Forum and statewide webinars
- COVID Response in 2020 to 149 families
- Ongoing support and advocacy for the needs of parents and caregivers and the organizations that support them

PC4W consistently amplifies the experience of parents and caregivers who need the following in order to meet the mental health needs of their children:

1. Availability of high quality mental health programs staffed by clinicians who are trauma-informed and experienced in addressing the issues presented by their child;
2. Concrete support for gaining access to care, including respite care, peer navigators, parent partners, and support groups;
3. Non-discriminating services that are close to home and affordable with insurance parity.



Through an annual Parent Voice Survey, focus groups, and comments made during events, families have reported that they are most concerned with their children's mental health needs related to anxiety disorders, prior trauma, attention and hyperactivity, and depression. They consistently report child behaviors such as inattention and not following direction, defiant behaviors, tantrums, and risk for suicide. Co-occurring concerns expressed by parents and caregivers tend to center around developmental disabilities, their child being bullied, or the need for educational support. Knowing how to advocate for and support their child's educational needs has been a particular concern this past year due to the closure of schools and stay at home restrictions.

Over the years United Parents has implemented a set of strategies to address these needs that includes a regional and statewide approach, development and dissemination of working tools for parents and providers, and close collaboration with others. United Parents engages in reflective practice to look at performance and results, and uses data to inform next steps and new directions.

In looking ahead, Parents and Caregivers for Wellness under the leadership of United Parents, will build on the strong foundation that was laid from 2017 – 2020. United Parents appreciates the continued partnership with MHSOAC to further address the heart of what matters to parents and caregivers. As a parent-led organization, PC4W is committed to moving away from the margins that barely touch the surface, to behavioral health innovation that will produce lasting change and improvement.



Experiences of Parents & Caregivers:

Current and Historical Trends

Families often find that the mental or behavioral health needs of one child affects every member of the family. When a child has intensive needs or difficulties, the needs of other children can be minimized or overlooked. Parents and caregivers who have a child with mental health or behavioral health needs frequently defer their own needs and in addition face stigma, social isolation, and frustration that appropriate resources for their child and family are not readily available. Accessing any resources at all often requires that parents and caregivers navigate complex service system requirements and waitlists.

Historically, parents and caregivers have reported that they have little or no access to policy makers or administrators, so that they can inform them of their actual, relevant needs. Too often programs have been geared towards meeting general needs, or those perceived by the policy maker or administrator, rather than informed by the actual voice of parents. Recently, in part through Parents & Caregivers for Wellness, those caring for children with a mental health need have had their concerns and issues directly sent to decision makers. However, many caregivers now report that they have “made their voice heard repeatedly”, but “nothing ever happens.”

Best practices for getting families “to the table” so that their voice can be heard include:

- Welcoming environment that offers child care and hospitality (a meal)
- Transportation access, in the form of a ride or stipend to offset the cost of travel
- Combining advocacy opportunity with another activity of interest to parents and caregivers, as well as their children
- Incentives through gift giveaways, such as gift cards
- Offering Spanish interpretation and other languages, if needed
- Not using mental health jargon and acronyms; avoid “alphabet soup” (See Appendix C.)

Best practices for “hearing” and following through on parents and caregivers stated needs include:

- Regular dialog and exchange between parents/caregivers and policy makers where action items are named and progress is reported
- Joint problem solving as part of the dialog and exchange
- Integrating one’s own lived experience and resilience into the work for affirmation and context
- Transparency with parents/caregivers on what needs cannot be met and why, or what can be done over time to address the needs
- Involving parents/caregivers in county-wide Community Planning Processes

Behavioral Health Issues Impacting Parents & Caregivers

Across three years of United Parents, from 2017 – Present, data clearly demonstrates that even before COVID-19 there was a crisis in Children’s Mental Health. PC4W has found that the trends over the past three years are consistent with the following statistics:

Only 5% of children with Medi-Cal receive a behavioral health service.	50% increase in mental health hospital days for children.	61% increase in the rate of self-reported mental health needs.	43rd in providing behavioral, social & developmental screenings.
104% increase in inpatient visits for suicide, suicidal ideation and self-injury for ages 1 – 17	70% of youth involved in CA’s juvenile justice system have unmet behavioral health needs and youth of color are over-represented.	Only 35% of youth who report needing mental health support actually receive it.	

The following needs have also been consistent across the span of PC4W:

What it Means for Children’s Mental Health	
Availability	A sufficient quantity of children’s mental health facilities, clinicians, and specialized providers without long wait listing for appointments
Accessibility/ Insurance Parity	Accessible for every child: non-discriminating, physical accessibility (close proximity), economic accessibility (affordable), and easy to access information.
Support for Access	Respite care, peer navigators/parent partners, support groups
Quality	Scientifically and medically appropriate and of good quality. Caring professionals who are capable, know about trauma, and can explain things in a way parents and caregivers can understand. Culturally relevant and respectful. This includes professionals being more understanding and empathetic to the parent struggles i.e. late to appointments etc.

Across all three years, parents and caregivers have been most concerned about their child’s behavioral challenges and mental health. Challenging behaviors, such as defiance, was identified as a primary concern for roughly 56% of parents. Furthermore, anxiety was a prominent concern for 64.3% of parents across years 2 and 3.

The specific Mental/Behavioral Health issues reported by at least 50% of participating parents and caregivers from the most recent (2019/2020) survey are:

Physical/neurological health	Mental Health	Behaviors
<ul style="list-style-type: none">• Special education• Developmental disabilities• Being bullied	<ul style="list-style-type: none">• Anxiety disorders• ADHD• Depression	<ul style="list-style-type: none">• Not following directions/inattention• Defiant behaviors• Temper tantrums

⁵ A PERFECT STORM FOR CHANGE: THE URGENT NEED TO ADVANCE CALAIM’S CHILDREN’S BEHAVIORAL HEALTH REFORM EFFORTS Overview and Call-to-Action June 2020 https://cachildrenstrust.org/wp-content/uploads/2020/06/CMHACY_CCT_CACFS_June25.pdf