



STATE OF THE COMMUNITY 2019 ANNUAL REPORT

Executive Summary

Parents helping parents.

In 2019, Parents and Caregivers for Wellness increased the number of family members involved, expanded our platform for reaching all stakeholders, and have strengthened the family voice in policy making by opening a Sacramento office and hiring a policy analyst to actively represent PC4W to inform and advocate legislative, regulatory and programmatic efforts. Through a collaborative effort, PC4W has begun to fill a significant gap that previously existed in California to provide statewide support to parents/caregivers who have a child with behavioral health needs, family members, and those who support parents/caregivers. Specific activities included:

- Community engagement and outreach
- Training and Education
- Local and statewide advocacy
- Linking families to resources

In 2019 parents and caregivers identified the following priority issues:

- Respite care for parents and caregivers
- Access to quality services and supports
- Whole person, integrated, individualized care

Stakeholder data collection was extensive in 2019 and included 793 surveys, 11 focus groups, and 35 key informant interviews with parents/caregivers and policymakers/

professionals. While the survey data yielded a quantitative statewide snapshot, the focus groups and key informant interviews gave meaning to the numbers and qualitatively provided a deep understanding of parent, provider, and policy maker perspectives.

Since the data indicated regional differences, the analysis looked at the needs of Los Angeles County (largest metropolitan area), urban counties, and rural counties separately. With responses from 44/58 counties this will allow for deeper understanding and use of data to tailor 2020 activities and events according to expressed need.

Current Landscape

The latest statistics from California Department of Health and Human Services (DHCS) indicate that only 266,915 children, or a mere 4.2% of those eligible, received even one contact from the public mental health system. The responsibility to deliver mental health services to children is shared by the Medi-Cal managed care plans (MCPs) and 58 different County mental health plans (MHPs) with no clear or consistent decision on which system is responsible for which types and intensity of services. The number of youth eligible for publically funded services in California is expected to increase significantly as SB75, which gives full scope Medi-Cal services to all undocumented youth in the state. For youth with other insurance, the outlook for



accessing timely and appropriate mental health services is no better. We remain hopeful and optimistic as recent policy changes have attempted to have services available where the youth and family can easily access them. This Annual Report paints a clear picture of the current landscape, and at the same time reflects the hope and optimism represented by the voice of parents and caregivers.

Child Concerns, Barriers to Services and Needs

Across all three geographical areas, caregivers are most concerned about their child's behavior, anxiety, and mental health needs (that vary widely by type). A significant portion of mental health needs indicated are thought by the caregiver to be associated with trauma exposure. Also, across all three areas, the number one reason cited for not receiving services was the slow pace of the process. All three geographical areas also indicated that the specific services their child needs are not covered by insurance or lack eligibility.

The data analysis also zoomed in on caregivers who were not receiving services. Regardless of age, race/ethnicity, sex/gender, specific mental health conditions, and community resources, all cited that slow service delivery is among the leading barriers to receiving care. When asked about their top concerns, the top two (2) reasons cited were anxiety about their child and concern about getting the most appropriate service.

When asked, "If you could advocate anything for your child, what would it be?" parents and caregivers overwhelmingly stated they wanted quality services that are specifically tailored to the needs of their child, and include a family component. Notably, some parents/caregivers said they would advocate for a stronger voice in establishing what their child needs (i.e., a mentor, sibling placement, mobile crisis unit). Next they cited system improvements that include greater transparency, system integration, and a faster, more streamlined process.

Desired Trainings and Present Curriculum

Comparison of existing PC4W curriculum with trainings wanted by parents and caregivers differed by geographical region. In Los Angeles County, PC4W offered mental health and family advocacy training that the parents wanted. There was an expressed desire to see more child safety and ACE's training workshops. In urban and rural areas, the PC4W trainings matched closely to future desired trainings. However, for urban areas, adding classes about navigating through an organizational system would be beneficial. And for rural areas, emphasis on keeping children safe when parents aren't around would be welcomed.

Next Steps

In light of these identified issues, PC4W will review and align training, and direct engagement and advocacy efforts to facilitate a coordinated system response. Data-informed recommendations are also offered for MHSOAC consideration.