Supporting Parents and Caregivers of Children and Youth with Mental Health Challenges
Parents and Caregivers for Wellness (PC4W) is a collaborative project, launched in 2017, to strengthen the voice of parents and caregivers and improve services and supports for families.

Project partners consist of parent and caregiver-run organizations and legal advocates for youth from across California, including lead agency United Parents (UP), California Alliance of Caregivers (CAC), California Mental Health Advocates for Children and Youth (CMHACY), and East Bay Children’s Law Offices (EBCLO).

Funded by the Mental Health Services Oversight and Accountability Commission (MHSOAC)

Activities include:
- Community engagement and education
- Training for parents and caregivers and those who support them
- Linking families to resources
- Local and statewide advocacy
Defining “Parents and Caregivers”

- Adoptive parent
- Biological parent
- Foster parents/resource parent
- Grandparent
- Family member (stepparent, aunt/uncle, etc.)
- Family friend
- Court appointed special advocate
- Guardian
- Legal representative
- Parenting teen or young adult
Parent Voice Statewide Survey Data

- Surveys available in English, Spanish, Vietnamese, and any Language requested
- 653 Parent Voice Surveys
  - 1/1/2019-2/1/2020 (pre-pandemic)
  - 44 counties
- 125 Parent Voice Surveys
  - 3/1/2020-3/1/2021 (pandemic/shelter in place)
  - 30 counties
- 471 Parent Voice Surveys
  - 3/1/2021-8/1/2022 (post peak period)
  - 47 counties
Training/Information Needs Expressed by Parents & Caregivers

- **Pre-Pandemic**
  - Advocating for family/self
  - Mental Health Services Advocacy
  - Advocating for system change

- **Pandemic/shelter in place**
  - Compassion Fatigue and Self Care
  - How to keep my child safe when I am not with them
  - Mental Health Services Advocacy

- **Post Peak Period**
  - Advocating for family/self
  - Compassion Fatigue and Self Care
  - Mental Health Services Advocacy

“7 people live in 2 brm apt. Need housing. Basic needs must be addressed before meaningful help can matter.”

“How those with developmental disabilities are served by agencies? How to get support for those served by the regional center system and mental health?.”

“My husband is 76 and I am 64. We need respite for 1-2 week a year for some time away from daily child care. We are willing to pay this ourselves if needed but can’t find anyone qualified to care for a difficult child.”

“PARENTS NEED RESpite!”

“PARENTS NEED QUALITY CHILDCARE!”
Concerns parents/caregivers have about the child/children they care for

- Pre-Pandemic
  - Anxiety
  - Mental health
  - Challenging behaviors

- Pandemic/shelter in place
  - Attention Deficit/Hyperactivity Disorder
  - Anxiety Disorders
  - Trauma

- Post Peak Period
  - Anxiety Disorders
  - Attention Deficit/Hyperactivity Disorder
  - Trauma
  - Depression

“I need help getting a house for my kids to run around and have space an apartment during a pandemic is too much for them”

“child does not trust adults to keep her safe”

“Need respite for parents. Very limited resources to help parents/families with aggressive child- feels like there is no help, overwhelming and discouraging at every attempt to help child succeed at schools teachers need education on emotional needs limited help for parents with LE. After hour help for aggressive older kid. Limited child mental health stays, only one in Sacramento and Bakersfield. Hospitals not equipped for 5150”
Which local agencies or individuals need to be trained about the needs of parents/caregivers and the child or youth they care for?

- **Pre-Pandemic**
  - Teachers
  - Social Worker/Therapist
  - School Administers and/or School Boards

- **Pandemic/shelter in place**
  - Teachers
  - Social Worker/Therapist
  - General Public

- **Post Peak Period**
  - Teachers
  - Social Worker/Therapist
  - School Administers and/or School Boards

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“Timeliness of assessments, support implementation, continuity of service providers”

“It's difficult to find a therapist that understands and knows how to help, and I think it would be more effective to have a therapist coach me as a parent on how to help my child.”

“Understanding what we as caregivers are going through and understanding where these children are coming from (trauma, etc.) and understanding that consistent rules with love is what is most helpful to them. Enabling them does not get us anywhere.”
What would parents/caregivers advocate for (in their own words)?

- “TRAUMA INFORMED TRAININGS FOR SCHOOLS. Helping schools understand trauma as a disability and how trauma functions in the classroom. Access to legal advocacy and help getting services through special ed processes.”

- “Better communication between school and mental health provider”

- “Faster turn time to get requested mental health support services. Dedicated therapists, not interns who leave in a couple of years.”

- “Ongoing residential placement (preferably near our home) for the children that are unable to live in a safe manner within a home environment. I would love for our daughter to live near enough that she can take part in family activities, but no within our home. We have no night shift or cooks or laundry and she cannot be safe in our home full time.”

- “Not only increase MH services, but increase EFFECTIVE services”

- “#1 RESPITE FOR THE CAREGIVER. Teach school district, educators and community professionals what it is really like to parent one of these children, so that they will have the understanding and knowledge of how to support the family.”

- “More cohesion between care systems to lessen the stress placed on families and children in assessing mental health care. Additionally, better access to mental health care for families and children across income and insurance spectrum.”

- “A consistent therapist that will continue with our child as he grows. He’s not outgrowing the trauma. It’s a part of him and he needs constant teaching.”
What Parents & Caregivers Want/Need

Every child should receive the right services at the right time and in the right amount, regardless of who insures the child or where they are located in the state.

**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 regardless of whether a parent or child has Medi-Cal or private insurance.

**Support for Access**

- Respite care/quality child care, peer navigators/parent partners, support groups

**Quality**

- Scientifically and medically appropriate and of good quality. Caring professionals who are capable, trauma informed, empathic, and can explain things in a way parents and caregivers can understand. Culturally relevant and respectful.

“It’s difficult to find a therapist that understands and knows how to help, and I think it would be more effective to have a therapist coach me as a parent on how to help my child.” - Parent/Caregiver
Why they are not getting the services their children need

Availability
- Don’t know what is available to help me
- Frequent change in service providers/high turnover
- Long wait times for services/slow process to receive services

Accessibility/Insurance Parity
- Services not covered by insurance/can’t afford services
- I/my child are not eligible for programs we need

Support for Access
- Respite care/quality child care, peer navigators/parent partners, support groups

“It is difficult to find providers who will accept our insurance. And when I find someone, I have challenges with keeping my son going.”

“Last therapy experience with my daughter was so negative that I have waited to jump back in and then covid hit, so online therapy is not appropriate for 4 year old and 7 year old. Now feel ready to go back to in person and there are just waiting lists...”
What is helpful/beneficial for parents/caregivers

- **Parent Partners (Peer to Peer Support)**
  - Parents and caregivers are enthusiastically connecting with other parents to exchange learning of what works and to be able to support each other in bringing their concerns directly to decision makers.
  - “Champion” parents are rising up in each county to facilitate bi-directional communication.

- **Holistic Approach**
  - Both parents/caregivers and the children they care for may need attention and services/supports.
    - This coincides with research indicating higher retention rates in treatment when the needs of both parents/caregivers and their child are attended to.
    - Parents/caregivers, as well as the children in their care benefit when systems and providers recognize they must strengthen both child and family well-being (Whole family).

  - “For the first several years, I couldn’t access or retain help because I was too dysregulated myself. Grateful that somebody recognized it so I could get treatment. But it would’ve been better if someone had helped me reign myself in earlier. NOTICE THE STATE OF THE MOM AND TREAT THAT FIRST.”- Parent/Caregiver

- **Communication between all child-serving agencies**

  “I have to say that to date most agencies act like some "secret organization". If you don’t ask the right question they don’t tell you about anything else except what you asked about.”- Parent/Caregiver
Empowering Parents & Caregivers Through Training and Education
Regional and Statewide In-person and virtual trainings

- 2,308 parents/caregivers
  - In-person: Meals/snacks, childcare, and incentives provided at each training
  - Virtually: snack magic snacks for participants, gift cards/incentives at each webinar

- 1,019 professionals/providers/parent partners
  - In-person and virtually

- Statewide Training
  - 1,354 parents/caregivers and professionals/providers/parent partners
  - Scholarships awarded to over 171 parents/caregivers
Local and Statewide Advocacy
United Parents Advocacy

- UP formed the Peer/Parent Certification Workgroup
- Monthly Children’s Mental Health Policy Updates sent out to parents/caregivers and child serving agencies
  - cover current legislation, budget issues, or other public policy issues.
- Annual Advocacy Day at the Capital
  - Parents/caregivers are able to talk to their senators/assemblymembers about the struggles and successes navigating California’s Mental Health System
  - Parents feel heard!

Thank you for all that your organization do for our state, parents, youth, and community. ..PRICELESS 😊💖
United Parents Advocacy Day at the Capitol

- Parents/caregivers are able to talk to their senators/assemblymembers about the struggles and successes navigating California’s Mental Health System.
- May 17, 2022, 43 parents joined us in person at the Sheraton Grand in Sacramento and 22 participants joined us virtually on Zoom to advocate for Assembly Bill 552.
- We met with 12 Senators/Assemblymembers.
- Parents were provided lodging, mileage reimbursement, meals, massages, art therapy, etc. etc.
- "Wow what a pleasure to be apart of a huge day! I was so nervous meeting with the Senate but you paired me with Marty and Judy and they both made it so much easier to speak from the heart! Thank you again for allowing my voice to be heard."

“I used to think my voice didn't matter in passing laws but after my participation in this I learned from the presenter's we are all in this together and we all matter.”
Outreach

- Most effective outreach tool:
  - Word of mouth and leveraging existing relationships with care providers/therapists.
  - to reach unserved/underserved populations:
    - Through cultural leaders and in locations where they traditionally gather i.e.: faith based organizations, cultural centers, home of cultural leaders, etc.
    - Attendance at local community events.
“A society where every child is valued for who they are, how they are. Capitalize on their strengths to create educational systems that work for them!”
Thank You!

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