Supporting Parents and Caregivers of Children and Youth with Mental Health Challenges
Who We Are & What We Do

● Parents and Caregivers for Wellness (PC4W) is a collaborative launched in 2017 by United Parents, California Alliance of Caregivers, California Mental Health Advocates for Children and Youth (CMHACY), Capital Adoptive Families Alliance, Children’s Law Center of California (CLC), East Bay Children’s Law Offices (EBCLO), and Young Minds Advocacy (YMA). Northern California Mental Health America recently joined the collaborative in 2018.

● 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
  • Local and statewide advocacy
2017 and 2018 Activities

- Regional/Statewide in-person trainings to **309** parents and caregivers and **302** providers
  - Oxnard/Ventura County
  - Chico/Butte County
  - San Dimas/LA County
  - 2018 California Mental Health Advocates for Children and Youth (CMHACY) Conference in Monterey, CA
  - National Alliance on Mental Illness (NAMI) California Conference in Monterey, CA

- **1,273** completed surveys
  - 1,123 parent/caregiver respondents
  - 39 provider surveys
  - 111 youth respondents
2017 and 2018 Activities cont...

- **19** Focus Groups
  - 114 parent/caregivers
  - 26 providers
- **11** Key Informant Interviews
- Advocacy with **9** local and **10** state decision makers/groups
- Subject matter expertise
- Outreach to:
  - **18,502** parents and caregivers
  - over **300** parent and caregiver run organizations and relevant parent/caregiver supports
Defining “Parents and Caregivers”

- Biological parents
- Kin caregivers
- Foster parents
- Adoptive families
- Legal representatives
- Court Appointed Special Advocates (CASA)
- Pregnant and parenting youth
  - Others?
Initial Needs Assessment: Common Themes

Needs:

- More respite care
- Educational Advocacy
- Quality child care
- General financial assistance
- Knowledgeable professionals
- A support system
- Support groups
- Therapy for caregivers
- Finding time to take care of our own needs
Initial Needs Assessment: Differences

**Biological Parents**
- Stable housing
- Overcoming fears of the “systems”

**Kin Parents**
- Legal assistance
- Financial planning for retirement years (grandparents)
- Financial support
- Respite

**Adoptive and Foster Families**
- Specific trainings for the unique needs of the children in their care
- Services AFTER the child is adopted
- Information about attachment
- Financial support
- Respite

**Legal Advocates**
- Coordination with child serving systems

**Parenting Youth**
- Child care
- Transportation
What did parents and caregivers tell us?
PC4W 2017-18 Statewide Survey

Available in English (electronically) and Spanish (hardcopy)

- 1,124 parents surveyed statewide
- Representing 49 Counties
- Primary respondents are biological families (55%), adoptive families (28%), Foster parents (18%)
- Age of youth cared for range from birth to 20 years old.
- Parents/caregivers report that 67% of the youth they care for have experienced trauma.
  - 83% family stress, 50% domestic violence, 38% physical abuse
“What people do not understand about our children and families is that adoption trauma is very difficult to work with as a parent. There is a belief that once children are adopted, it is happily ever after since now the children are in a loving home. The truth is that we are often adopting children that are coming from such dire circumstances that they could never go home. Their trauma, grief and loss is so overwhelming and huge that it permanently effects brain development and results in extremely challenging behaviors. Often these behaviors do not emerge until the children feel safe and are living in their homes for a while and the adoption is finalized. At this point, many services have been cut off and are no longer available. Parents are blamed because the children have been living with them for a while. The truth is there is no adoption without trauma. The stress this places on caregivers, families, and children can be enormous. We need to be understood and have appropriate services available without making things worse. “- Anonymous Parent/Caregiver
What concerns do parents have about their children?

- Attention Problems: 54.52%
- Challenging Behaviors: 54.42%
- Mental Health: 49.76%
- Special Education: 38.34%
- Developmental Disabilities: 31.97%
Do parents get what they need?

If not, why not?

I don’t know what is available to help me or how to find resources (37%)

Not enough time in the day to access services/supports (33%)

The services and supports I need are not available in my community (28%)

I/my child are not eligible for programs we need (26%)

I get too overwhelmed (22%)

I cannot get anyone to listen to me when I ask for help for my child or myself. (20%)
“My children are receiving support and services they need, I myself don't feel supported as a parent and struggle with feelings of burnout.” - Anonymous Parent/Caregiver
“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.” - Anonymous Parent/Caregiver
## Training/Education

### NEEDS

<table>
<thead>
<tr>
<th>Need</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>How to keep my child safe when I’m not with them</td>
<td>44%</td>
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<tr>
<td>Advocating for System Change</td>
<td>39%</td>
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<tr>
<td>General Support</td>
<td>38%</td>
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<tr>
<td>Advocating for my family</td>
<td>34%</td>
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<tr>
<td>General Education Information</td>
<td>23%</td>
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<tr>
<td>How my home environment can affect my child/children</td>
<td>22%</td>
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### PREFERRED METHOD OF RECEIVING TRAINING

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<th>Method</th>
<th>Percentage</th>
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<tr>
<td>In a group - listening to an educator/trainer</td>
<td>61%</td>
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<tr>
<td>Written - electronic (website, tablet, e-reader)</td>
<td>58%</td>
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<tr>
<td>In-person - one on one listening to an educator/trainer</td>
<td>56%</td>
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<tr>
<td>Written - paper, booklets, manuals, etc.</td>
<td>38%</td>
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<tr>
<td>Videos - listening to a trainer, watching examples</td>
<td>36%</td>
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Which local agencies or individuals need to be trained about the needs of you and the child or youth you care for?
“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.”- Anonymous Parent/Caregiver
What topics do you think would be helpful to the local agencies or individuals listed above to understand your family’s needs?

- The needs and strengths of the youth I care for (61%)
- Understanding what I need to better care for my child or youth (58%)
- Information about how to provide the best care to me and my family (57%)
- Information about state and federal laws and regulations (42%)
- Information about what I need to keep my family healthy (39%)
Do parents know who makes decisions that impact them?

- No: 81.61%
- Yes: 18.39%
“I think if the decision makers and policy makers at the state level could have conversations with the caregivers in the trenches before making such sweeping changes it would be a very good thing. Many pitfalls could be avoided and a better outcome with consensus from the caregivers could be achieved.” - Anonymous Parent/Caregiver
How do parents/caregivers find out about services and supports?
“We are struggling to keep it together”
Professional advice/perspective

➢ “We need money, we’re amazing, underfunded, kids deserve more attention than we’re giving them. Too many cases for social workers and attorneys.”

➢ “We think that a MAJOR unmet need is for parents to be able to receive mental health services at the same place as their child. There seem to be a fair amount of places for children to go, but very little for parents to receive services. We think that specifically for biological parents of children in dependency, another MAJOR service need is for parents to receive some evidenced based in-vivo coaching during their supervised visits to help facilitate better visits (and better stabilization trajectories in the long run).”
What did our youth tell us?
Do they think their parent/caregiver understands them?

- Sometimes: 48.57%
- Almost Always: 40.95%
- Never: 6.67%
- Other (please specify): 3.81%
What do they wish their parents knew about their needs?

- Listening is important! I don't need solutions, just someone to say, 'wow, that sucks.'
- Sometimes I don't want to talk.
- More about needing to talk with confidentiality, i.e. not telling my dad.
- I think it's hard for parents to understand what happens at school - High school stress.
- Sometimes I need to be checked in on.
- That my mental health is more than a diagnosis.
- I wish my parent knew I was struggling with my mental health
What do they wish their parents knew about their strengths?

- That I try my hardest
- I’m more resilient than I look
- That I can and do believe in myself
- I’m very responsible
- I am strong
- I am actually really creative and I wish I was encouraged to pursue that more
What are the top five things that their parent/caregiver can do to support them?

Help with School
Give me space
Make sure I eat healthier
Talk to me about everything when I’m sad
Emotional Support
Emotional availability
Love
Keep me connected with the extended family
Not criticize me first
Not be judgmental
Give affirmations
Give me space
Reliable
LISTEN!
Pay tuition
Check in
More freedom
Hug me
Food
Call or Text more often
Talk
Positivity
Leave me alone
Sit with me
Give me more attention
Be supportive of me being queer
Ask me how I am
Trust my decisions
Ask me how my day was
What supports do parents/caregivers need to support the youth?

- Education on my diagnosis
- Knowing when to connect me to professional help
- Connect with other adults with children my age
- Understanding my generation
- Understanding the stress I face at school
- Their own therapy
Questions and Wrap-up

Partner with us!

- Take our survey or send it out to your clients/community members
- Share your experience with mental health decision-makers
- Attend or outreach for our regional trainings and outreach events
- We want to know what’s happening in YOUR community
- Like us on Facebook