



ACCESSING MENTAL HEALTH SERVICES & SUPPORTS: Families' Experiences

INTRODUCTION

COVID has had a negative impact on all of us. For families of children with mental health needs, the impact has been profound. Families have always had to work hard to find the right supports and services for their children. COVID has made it considerably more difficult, if not impossible. Families are dealing with more now than before COVID. Services and supports have vanished, and their child's mental health needs are more complex, severe, and urgent.

SURVEY BACKGROUND

PPAL surveyed families to learn what effect COVID has had on children's mental health and the ability of families and caregivers to obtain needed services and supports. We also asked how families and caregivers have been rebuilding services and supports since COVID restrictions have lessened. Family responses indicated that:

- children had increasingly complex needs;
- they experienced significant challenges in accessing supports and services; and
- they needed more information and strategies to support children

RESPONDENTS

The demographics of the respondents are

- **274** families raising children up to 26 years old
- **91%** had children with mental health needs
- **1 in 3** of these children also had special health care needs
- **65%** of the children included in the survey were identified as white and **35%** were identified as children of color
- **58%** of caregivers reported having a strong understanding of their child's current mental health needs or behavioral challenges

NEEDS AND GAPS

NEEDS intensified.

Children of all ages and racial backgrounds are exhibiting more, and more severe, symptoms.

GAPS persist.

Families are finding it harder to access clinical treatment, school supports, and community resources.

“We were already waitlisted BEFORE COVID. COVID began. The need for services grew exponentially. Wait lists were even longer. My child could not get ANY in-person support for over a year. He ended up with multiple suicide attempts and 5 hospitalizations.”

Children's Mental Health Got A Lot Worse

MORE SYMPTOMS FOR MOST CHILDREN

Families reported that their children exhibited a greater number of behavioral health challenges.* The percentage of children with **FIVE OR MORE** behavioral health challenges* rose by 13%. This was true across **all** age groups and **all** racial backgrounds.

Children with 5+ challenges: Before COVID **30%** 2022 Survey **43%**

*Challenges: problems with focus or attention; anxiety; extreme moods such as depression; problems sleeping; withdrawn; hallucinations; difficulty controlling their behavior; aggressive behaviors; difficulty communicating

NEEDS SHIFTED AND INTENSIFIED

Anxiety. Extreme moods. Problems sleeping. These needs increased most for surveyed children, pointing to the increased intensity of children's challenges. Anxiety became the number one challenge in the survey, and extreme moods such as depression moved from the fifth spot to the third spot.

BEHAVIORAL HEALTH CHALLENGES	BEFORE COVID	2022 SURVEY
Shows a lot of anxiety	61%	74% +13%
Problems with focus or attention	71%	73%
Extreme moods such as depression	38%	49% +11%
Problems sleeping	40%	49% +9%
Difficulty controlling behaviors	45%	48%
Difficulty communicating	43%	45%

IMPACT OF SHIFTING NEEDS

Families shared one example after another illuminating how hard it has been to find adequate support for their children. They also highlighted the consequences of not having support, especially where it hampered the families' ability to keep their children safe - a difficult situation for the children and caregivers.

“What is usually extremely hard **feels impossible now.**”

“I'm more connected than most parents but can't find what he needs **WHEN** he needs it. So **it's ALL ON ME** to be there for him to build coping skills and be his crisis management team. That's a lot on me and I have more resources than others.”

“Covid disruption sent my child in a **tailspin** that has **worsened over time.**”

Challenges Finding Services & Supports

RESOURCES DISAPPEARED / HARDER TO FIND



70% of caregivers reported increased difficulty finding clinical treatment for a child.

Survey Question: TODAY , is it easier or harder to find these supports & services for your child than it was before COVID?	Harder
Clinical treatment (examples: therapy, medication management, inpatient treatment)	70%
School support	45%
Community resources (examples: sports, music classes, social activities)	47%

IMPACT OF REDUCED SERVICES & SUPPORTS ON FAMILIES

- ➔ Families can't count on past services working or being available.
- ➔ Families need to either rebuild supports for their children or find new supports for their children.
- ➔ Families are drained and impacted financially.

The system has broken down to the point that necessary therapy and psychiatry services are not available and everyday functioning is declining as a direct result. The standard of care has declined even where services are available.

Out of 8 providers we only have 2 left.

We only have services now because we pay \$\$\$\$ out of pocket.

I'm usually really good at finding resources for my child, but there is such a shortage in the mental health field.

The time and resources required from a parent to advocate for resources is very draining and time consuming, especially when the parent has to work full time.

Families Want More Knowledge and Support

40%

of caregivers shared that their child needed them - the caregiver - **to have additional information and support.**

WHERE DO CAREGIVERS LOOK FOR INFORMATION AND RESOURCES?



Medical Community & Schools

- 64% child's therapist, psychiatrist, team
- 28% child's teacher
- 27% child's pediatrician

This highlights the need for all providers to be armed with reliable information and know how to communicate it to the families and support them in their efforts to help their children.



Other Caregivers & Family-Run Organizations

- 43% family-run organizations, like PPAL, Federation for Children with Special Needs, NAMI
- 29% online resources, like Facebook groups

TOP TIPS CAREGIVERS GIVE TO SUPPORT OTHER FAMILIES

Caregivers utilize a wide array of strategies and information when looking to find support for their loved ones. Across **all ages**, the highest recommendation provided by caregivers to others looking for support for their children was to **BE PERSISTENT** (67%).



BE PERSISTENT.
Keep Calling.

67%



CALL A FAMILY-RUN ORGANIZATION, like PPAL, Federation for Children with Special Needs, or NAMI

52%



ASK PROFESSIONALS
who know their child

such as a therapist or pediatrician

41%



TALK to other parents/caregivers online, such as in Facebook groups

36%



JOIN A SUPPORT GROUP

29%

Where Do We Go From Here?

FAMILIES AND CHILDREN CAN'T WAIT.

Children don't get to be 10 years old again or have a second chance at high school. They've lost time precious time during COVID. They will lose more without swift, effective interventions. More must be done NOW to address their heightened mental health needs.

NOW'S THE TIME TO FILL THE GAPS.

While waitlists remain long, and services and supports remain difficult to obtain, families actively seek support for their children from family-run organizations, support groups, and more. Research supports that families benefit from family-led support. Families suggest the following low-cost/low-barrier ideas to help fill the gaps.

- ↑ Family navigator support
- ↑ Family-led support groups
- ↑ Parent education/coaching
- ↑ \$\$\$ to pay for respite care
- ↑ Support while on waitlists
- ↑ Support when in emergency department
- ↑ Real opportunities to effect change for systems

HOLD HOPE FOR PROJECTED SYSTEM CHANGES AND WORK HARD TO IMPROVE THEM.

The roll out of the Massachusetts Behavioral Health Roadmap (which includes the Behavioral Health Help Line, Community Behavioral Health Centers, Youth Community Crisis Stabilization Programs, and more) offers hope for families, as do efforts for true insurance parity, additional hospital beds, increased workforce, school-based mental health services, and more. All of these changes will take time and patience. In the meantime, we need to talk together about what's working and what's not, and fix what's not working. And by "we", PPAL means ALL - all individuals, families, organizations, providers, hospitals, and state agencies affected. True collaboration provides hope.

This report is based on PPAL's Summer 2022 Survey, *WHAT'S HELPING YOU REBUILD? Finding what your child needs post COVID*. This survey was supported by a SAMHSA grant.

The Parent/Professional Advocacy League (PPAL) is a statewide family organization dedicated to improving the mental health and well being of children, youth, and families through education, advocacy, and partnership. <https://ppal.net/>