

Speak Out for Access – Take 2

A PPAL Pop-Up Survey

Spring 2016

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Parent/Professional Advocacy League



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Background Parent/Professional Advocacy League (PPAL) is celebrating its 25th anniversary with a series of “pop-up” surveys, in an attempt to measure whether family experiences with the mental health system have changed over the years. The original *Speak Out for Access* survey was sent out in 2001. The present survey, *Speak Out for Access - Take 2* focused only on care in the community, but asked about access again. The results show that not enough has changed. PPAL relies on feedback from parents and is very grateful to everyone who participated.

Top findings

- In 2001, 7% of parents reported that their children were uninsured; that number has dropped to zero by 2016. However, even with insurance coverage, 83% report that access to care continues to be difficult for families.
- The number of children waiting over a year to access treatment has dramatically decreased from 33% in 2001 to 25% in 2016, yet other wait times remained nearly the same.
- 47% families said that school officials did not understand mental health problems in children.
- When a new community based health provider as needed, the time between locating a provider and getting an appointment was less than a week for only 9% and took more than three months for 41% of families.
- 38% whose children whose children are covered by MassHealth say access has become easier over the last 5 years, while 35% whose children have private insurance say access has worsened.

“There is no help, guidance, understanding or kindness bestowed to those straddling to battle mental health disorders or their parents who give up their lives to advocate for them. The system is very broken. If they had cancer or diabetes, they would receive the best care paid for by insurance with compassionate doctors. So sad.” – one parent

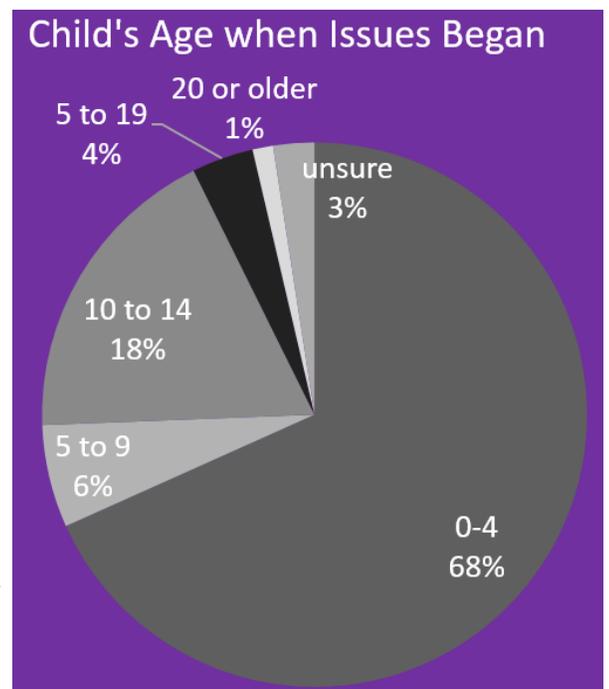
Methods This first pop-up survey asked parents about access to mental health care for their children from babies to 26 year olds. This survey was distributed for three weeks in February and March 2016, via social media and email. We asked eighteen questions: five were demographic, three were Lickert scale, and one was open-ended. More than a hundred parents responded; fifty-two wrote about their experiences in the last open ended question.

“Accessing care is abominable. To receive acute care, you need to be homicidal or suicidal.” – a mother

Demographics Most respondents had children who were 19 or older (47%) and only one respondent had a child under the age of five. The vast majority were white (87%). The most prevalent diagnosis was Anxiety Disorder (61%), followed by ADHD (45%) and Depression (44%), then followed by Post Traumatic Stress Disorder (30%) and Bipolar Disorder (29%). The majority (55%) showed their first sign of a behavioral health issue before the age of five and another 25% by age 9. The majority of children receive care from a psychiatrist (61%), social worker (30%), psychologist (27%) or therapist/counselor (52%) and only 16% receive mental health care from their pediatrician. Parents continue to say, *“There are not enough trained, competent providers.”*

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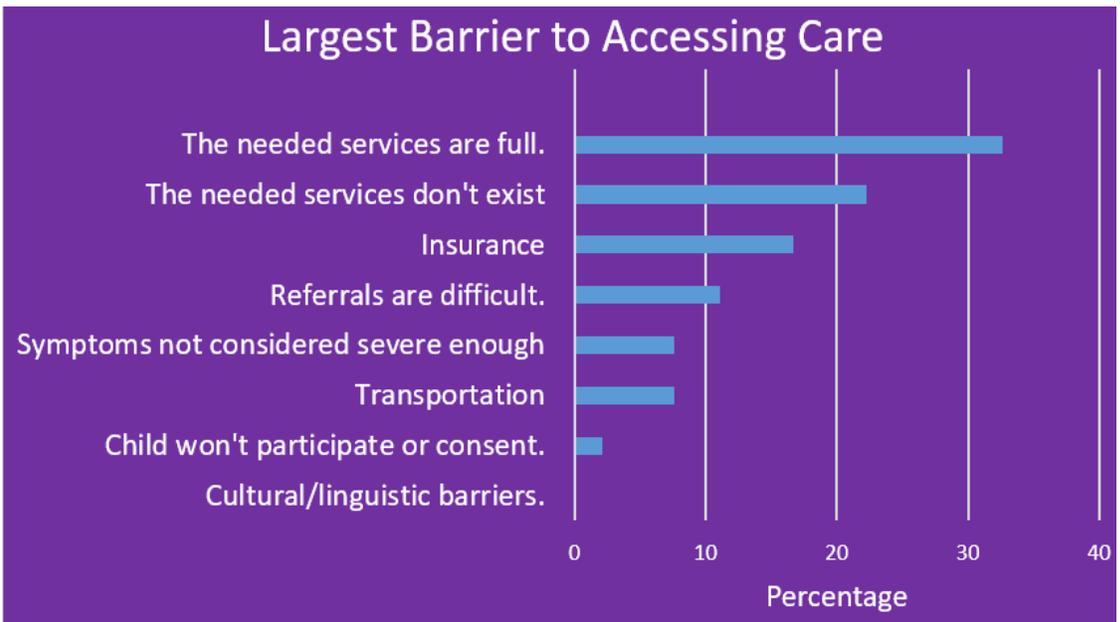


56% of parents said their child was on an IEP, and 8% had a 504 plan. 23% said their child goes to a therapeutic day school or a collaborative school, and only 12% said their child receives no special education services.

Access to care in the beginning Respondents reported that 55% of their children first displayed signs of a mental health need before age 4, slightly higher than in 2001 (48%). The percentage of children whose parents reported they still not receiving care as often as they need has stayed almost the same from 9% in 2001 to 7% in 2016. 83% say there was a delay in getting care. Of those who experienced a delay nearly 1 in 3 cited the cause being that services were full or they couldn't get an appointment (28%), down from 39% in 2001. 14% reported that the services their child needed did not exist whereas in 2001 only 11% chose this answer. The percent of parents who didn't realize their child needed care (and waited) remained the same at 10%. The number who reported their pediatricians didn't think they needed to seek care dropped from 17% (2001) to 14% (2016).

Access to different kinds of care When a new provider was needed, less than 9% of families were able to get an appointment within a week, and 41% had to wait more than three months. 24% reported that they experienced *a lot* of difficulty finding a new provider. ***"We think this is a tragedy!"*** one parent commented. Even once a family finds a mental health care provider, parents say ***"what's promised is rarely delivered."***

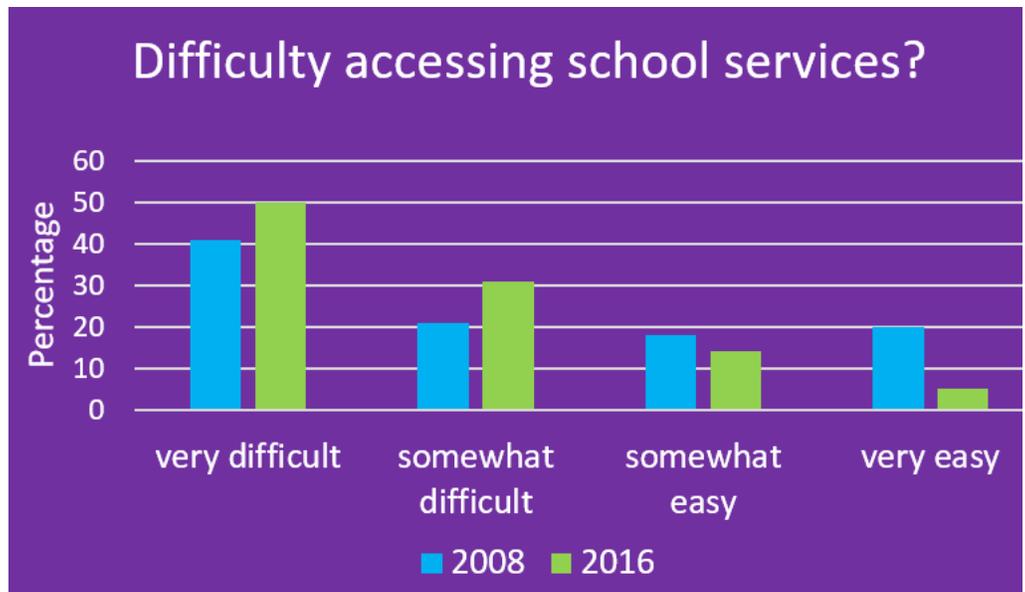
Insurance was cited as the largest barrier to accessing care. For example, a large group of parents reported that insurance would not cover the services or that the co-pay was too large (22%). This was true for 18% of families whose child was covered by MassHealth, 23% of families who had a child on private insurance, and 33% of families who had a child covered by



a combination of private and government insurance. Many parents whose children are covered by MassHealth believe that access to mental health care has become easier over the last five years (38%) while only 29% of families whose children are covered by private insurance thought access had improved. 28% of families whose children have MassHealth coverage thought access had worsened compared with 35% of families whose children have private insurance coverage reporting poorer access. In each group about a third did not think access had changed.

Access to care in the school system Only 25% of families are satisfied with the care their child receives at public school and 47% said that school professionals do not understand mental health issues (in 2001 this was 50%). Parent after parent complained, *“Schools haven’t the foggiest notion of what to do and are hampered by outdated assumptions and prejudices.”* When mental health care is needed at school, 81% of families had difficulty accessing it. Only 11% are satisfied with school services. Of those on an IEP, 75% find it difficult to access necessary school services

(43%, very difficult). Of those with children in a group home, residential therapeutic day school or collaborative program, 70% find accessing necessary school services difficult (47% very difficult).



“For years the school fought against providing services as I watched my children struggle.”
-- a parent

Conclusions There have been many changes in the children's mental health system over the last 15 years, yet parents still report difficulty in accessing care. In 2001, many thought that by ensuring that all children had insurance coverage, difficulties with access would improve. This has not proved to be true. 35% of families believe that access to care has gotten easier over the past five years, while 17% think it has gotten *much* more difficult. In addition, parents have found the most help from other parents (42%), family organizations like PPAL (39%) and the Internet (27%) while few have found help with access from their insurer (6%) or helplines like 211 (3%). Access to mental health care is still a top concern in the minds of parents in Massachusetts and strategies to improve that access should be a top priority.