

# Stigma: What Families Say

A PPAL Pop-Up Survey

Lisa Lambert & Emma Brandl Denson

Parent/Professional Advocacy League



This project is funded by the Massachusetts's Department of Mental Health

**Background** 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. We have asked parents questions about stigma in many of our surveys over the years and, even when we didn't ask, they often volunteered how stigma has impacted their lives. This survey revisits many questions asked previously as well as adding new ones that draw on experiences relayed by families in past surveys. Questions focused on information sharing, feelings of being blamed, difficulties with school staff who misunderstand or label children and whether stigma has lessened over the last few years. We rely on feedback from parents and are so grateful to everyone who participated.

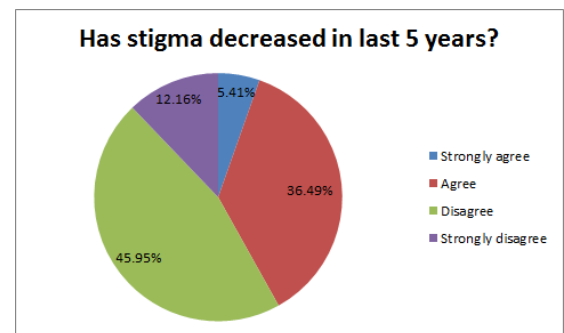
## Top Findings

- Many parents felt they they played a part in causing or worsening their child's mental health problems. 1 out of 2 parents blamed themselves for not advocating for their child sooner. 40% blamed family history of mental health problems. Far fewer put the blame on their parenting style.
- 1 in 4 reported that their child had been treated differently by the emergency room staff when seeking treatment for a medical problem, once the staff found out the child had a mental health diagnosis.
- 57% worried that their child's future career might be impacted if their child's mental health information was shared with others.
- Almost half (47%) reported that they trust the special education staff at their child's school to understand and support their child's needs, up slightly from a 2009 PPAL report. However, trust in other school staff including guidance counselors and school nurses decreased over the same time period.
- 58% stated that stigma has either stayed the same or increased in the past 5 years despite celebrity stories and anti-stigma campaigns. 74% reported a personal experience with stigma.

*“Stigma is out there, but the more we share our lives with others and educate them when they don't understand, the more we can hold our heads high despite knowing (or maybe just feeling like) we are being judged harshly by others. It's the only way we can change the future. Stop the stigma!” – a mother*

**Methods** This pop-up survey asked parents a series of questions about the stigma they've experienced related to their child's mental health problems. This survey was distributed for four weeks in April and May 2016 via social media and email. We asked nineteen questions: of those, five were demographic and one was open ended. Seventy-eight parents responded; thirty-four also took time to write about their experiences in the last open ended question.

**Demographics** The majority (67%) of the respondents had children between 6 and 18 years, although many respondents had older children (32% were 19-26 years). Less than 2% had a child under the age of 5. The vast majority were white (83%) with 8% identifying as Latino and 3% as African American. 32% reported that their child was covered by private insurance, 41% said their their child had MassHealth and 26% said their child was covered by a combination of private insurance and MassHealth. Children had a variety of diagnoses and every child had received at least one diagnosis. Nearly all children had more than one diagnosis. The most common diagnoses were anxiety disorder (63%), ADHD (47%), depression (44%), learning disability (40%), post traumatic stress disorder (37%) and bipolar disorder (27%). 24% of respondents identified additional diagnoses such as Tourette Syndrome, persistent sleep problems and reactive



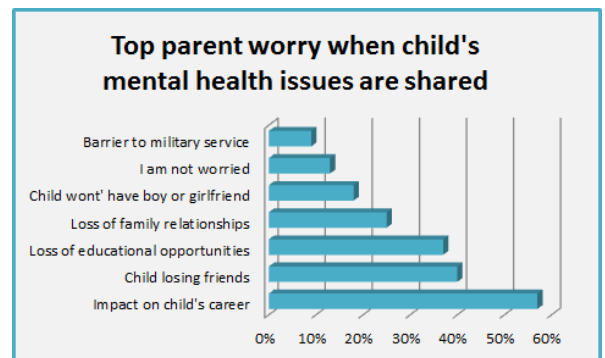
attachment disorder.

**Impact of Sharing Information** The vast majority of parents (63%) were comfortable with their immediate circle of friends and family knowing that their child takes psychotropic medication. Nearly one-third (27%), however, reported they were uncomfortable having family and friends know their child was on medication or had a diagnosis. 10% reported that their child was not taking medication at this time. However, parents expressed a range of concerns about sharing mental health information outside this small circle. The largest worries were that their child's future career might be impacted (57%), their child might lose friends (41%) or not have educational opportunities (37%). In a recent survey of 2061 adults by YouGov in Great Britain, researchers found that 49% of parents worried that if their child had a mental disorder, they would never meet a partner or have children. 48% also feared they would be unemployed. The findings are similar to this survey.

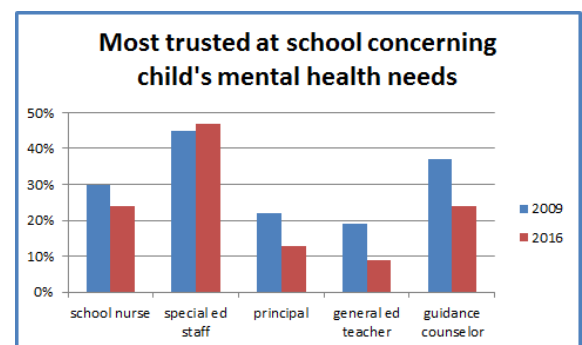
**Stigma and Schools** Parents consistently expressed concerns that school staff lack understanding of mental health issues in children. They consequently worried about sharing mental health information with school staff. They also worried that school staff misinterpret information. In a 2009 survey, PPAL asked parents who they most trusted with regard to their child's mental health needs among school staff; this question was repeated in this survey. Results show that trust in school staff has decreased since 2009. The largest group (47%) expressed trust in special education staff followed by school guidance counselors (24%) and school nurses (24%). Far fewer trusted administrators such as principals. The only group for whom parents reported increased trust were special education staff. Each of the other groups received less trust than in 2009 (see chart).

Parents also reported that school staff used labels to describe their child, even when informed that the child's behavior was a result of mental health issues. Only 14% reported that the school does not mislabel their child. 27% said their child was labeled non-compliant and 24% said their child was called disruptive, even when staff knew that these behaviors were symptoms of the child's diagnosis. Other terms that parents reported were lazy (16%), inattentive (33%), stubborn (12%), willful (10%), clumsy (5%) or incorrigible. Only 1 in 4 (23%) parents reported that the school does not blame their child for their own mental health symptoms. Another 23% reported that their child is not in school at this time, but noted that this type of labeling had been used previously.

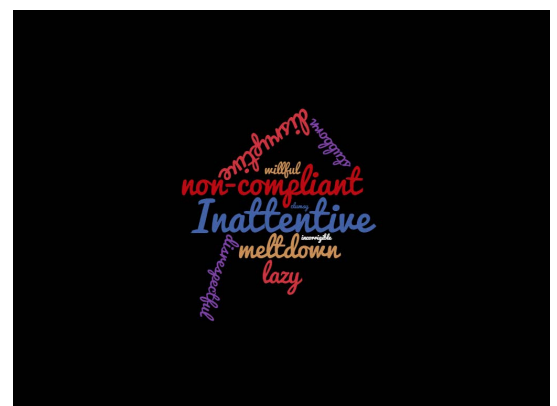
**Impact of Stigma** Parents worried that attitudes about mental illness would impact their child's life and reduce opportunities that



*A friend "broke up" with me because my daughter was depressed and cutting. She was afraid her daughter would also cut.-- a parent*



*My son was bullied by his teachers at high school. He was called lazy, silly, bored, etc. In several IEP meetings they refused to acknowledge his mental health issues. One teacher even said his behavior was learned at home. -- a mother*



might otherwise be available. When asked if they thought stigma had decreased over the last five years, 58% said that stigma had stayed the same or gotten worse. Only 5% said they strongly agreed that stigma had decreased. This is in line with a 2010 study which found that while Americans have developed a greater awareness of the neurobiological basis for mental illness and are more supportive of treatment, stigma is still significant and in some cases, has actually increased. One mother wrote, "I am worried about revealing the diagnosis even though I know it's important to share information to get care for my child." The majority (74%) reported a direct, personal experience with stigma.

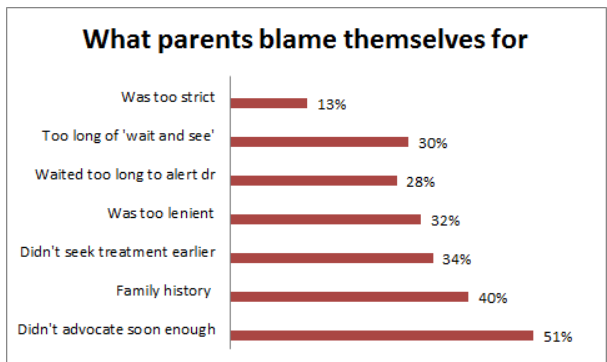
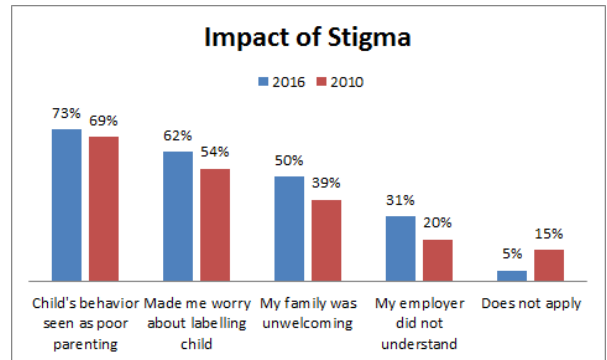
In a 2010 survey, PPAL asked if stigma had ever resulted in their parenting being criticized, their family shunning them or difficulties with employment. In this survey the question was repeated and families increasingly reported that stigma had created enormous impact in each category (see chart). The increases were greatest in how extended family behaved, difficulties with employers and concerns about the impact of "labeling" a child with a mental health diagnosis. Fewer parents reported that their parenting skills were being blamed for their child's behavior than in 2009. One mother wrote that she worried "that my child will be affected in multiple ways by the stigma of 'crazy people'." Another said that due to her child being "unable to regulate emotion, he was ostracized in the neighborhood."

Self stigma occurs when people internalize society's negative attitudes about mental illness. Many parents can feel that their parenting, their genes or failing to recognize problems earlier has partly caused or contributed to their child's mental health problems. Unsurprisingly, parents blamed themselves in a variety of ways. More than half (51%) said they didn't advocate for their child soon enough. Similarly, many parents reported that they waited

too long or until their child's symptoms became significant (30%) or didn't bring their child's problems to the doctor's attention quickly enough (28%). A significant number believed that their family mental health history was to blame (40%). One mother wrote, "I have felt very self-conscious about my own family's history of mental illness." Fewer parents blamed themselves because they were too lenient (32%) or too strict (13%). Even so, some said their families were quick to point to parenting style as a cause. One wrote, "I have family who tell me that I need to spank my child when he misbehaves and tell me I am too lenient as well. They say I should hit my child or bite him back."

Self blame or finger pointing by extended family was greater than any blaming parents reported from school systems. Less than 3% reported blame assigned by their child's providers. "We are trying to stay the course, one parent wrote. "But I always worry about how others see him. And us."

With my first child, I definitely felt blamed, mostly by school and family. With my second child, I knew how to educate those who were inclined to judge. -- a parent



I have been told to control my kid better or that he needs a slap on the butt to straighten him out.--a parent