Stigma: What Families Say

A PPAL Pop-Up Survey

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

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

Impact of Stigma

<table>
<thead>
<tr>
<th>2016</th>
<th>2010</th>
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<tbody>
<tr>
<td>Child's behavior</td>
<td>73% 99%</td>
</tr>
<tr>
<td>Made me worry about labeling child</td>
<td>62% 54%</td>
</tr>
<tr>
<td>My family was unwelcoming</td>
<td>50% 39%</td>
</tr>
<tr>
<td>My employer did not understand</td>
<td>31% 20%</td>
</tr>
<tr>
<td>Does not apply</td>
<td>5% 15%</td>
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What parents blame themselves for

- Too strict: 13%
- Too long of 'wait and see': 30%
- Waited too long to alert Dr: 28%
- Was too lenient: 32%
- Didn't seek treatment earlier: 34%
- Family history: 40%
- Didn't advocate soon enough: 51%

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."

PPAL
Summer 2016