

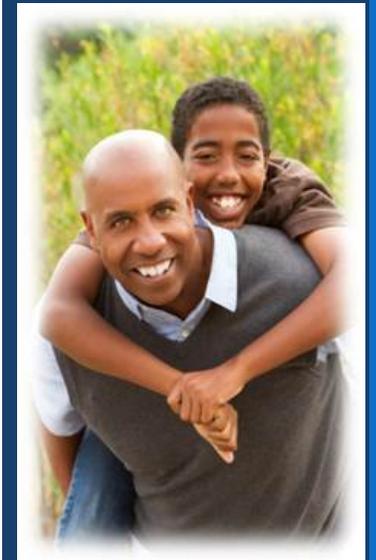
Medication & Choices – Take 2

A PPAL Pop-Up Survey

Spring 2016

Lisa Lambert & Emma Brandl Denson

Parent/Professional Advocacy League



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



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 first *Medications & Choices* survey was sent out in 2006, when national headlines asked if America was overmedicating children and the black box warnings on antidepressants had just been issued. The present survey, *Medication and Choices -- Take 2*, was sent to parents 10 years later to revisit many of the same topics as the first survey. It focuses on key questions concerning medication use, satisfaction and worries, as well as alternatives to medication. PPAL relies on feedback from parents and is very grateful to everyone who participated.

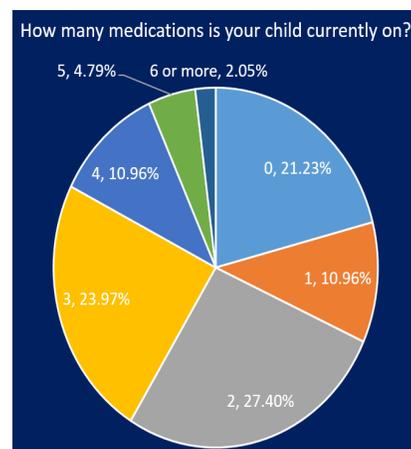
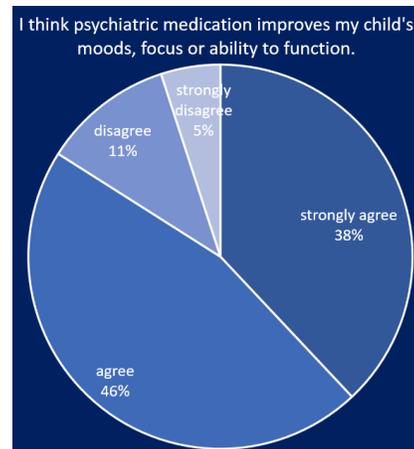
Top Findings

- In 2006, 85% of parents reported that their child had had only one prescriber; in 2016, only 21% have stayed with one prescriber and almost 20% have had 6 or more people prescribing psychotropic medications for their child
- The average number of diagnoses parents reported rose from 3 to 3.7 with some children having many more
- 75% of parents believe that psychiatric medication improves their child’s moods, focus or ability to function
- 82% of parents found the process of trying out medications or combination of medications to help their child difficult and frustrating
- 76% of parents worry often about their child being over medicated or that their medications may be dangerous; only 18% of parents do not share those concerns

“It took a long time to agree to medicate our daughter, then a long time to get the right meds, but in the long run I regret not having tried medication earlier.” – a parent

Methods This survey asked parents about medication as a treatment for emotional, behavioral and mental health problems experienced by their children, from toddlers to 26 year olds. This survey was distributed for three weeks in March and April 2016, via social media and email. We asked seventeen questions: five were demographic, three were Likert scale, and one was open-ended. A hundred fifty parents responded; eighty-five wrote about their experiences in the last open ended question.

Demographics Many respondents had older children (35% were 19 or older) and less than 2% had a child under the age of five. The mean age was between 16 and 17; in 2006 the mean age was 13.4 years. The vast majority were white (89%) with 5% identifying as Latino and 2% as African American. 40% reported that their child was covered by private insurance (compared to 62% in 2006), 39% said their child had MassHealth (in 2006 it was 55%) and 22% said their child was covered by a combination of MassHealth and private insurance (18% in 2006). 65% of respondents reported that their child's medications are being prescribed by a psychiatrist, with an additional 20% stating the prescriber was a pediatrician or family practitioner.



10% had their medications prescribed by a nurse practitioner; several more were waiting for an appointment with no one monitoring their medications, some just out of an inpatient bed.

Medication trials and prescribing

While the percentage of children taking 2-3 psychotropic medications has remained roughly the same since 2006 (53% in 2006, 50% in 2016), the number taking 4 or more medications has significantly dropped (25% in 2006, 18% in 2016). However, there has been an increase in the number of medication trials required before the child finds a dosage or combination that works. In 2006, 23% of children found a medication that worked after trying 1-2 medications, in 2016 that was true for only 11%. Almost half (45%) had to try 3-6 medications before finding a successful combination of medications (39% in 2006). 9% of families have tried more than ten medications for their child, and an additional 1.5% have tried more than twenty medications. One mother wrote, "Medication trials are just brutal."

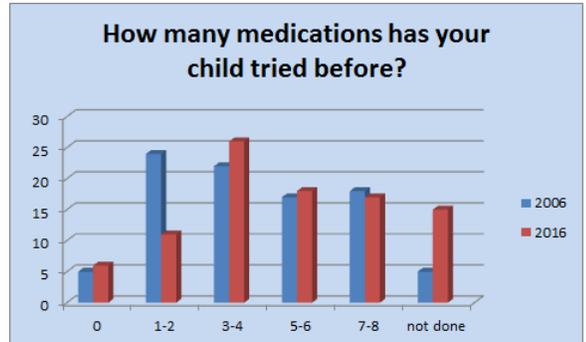
The lack of continuity in prescribers for children is startling and may be a contributing factor. In 2006, 85% reported their child had had just one prescriber. In 2016, only 21% report having a single prescriber. 40% have had two to three different prescribers since being diagnosed; 17% have had up to five prescribers, and 18% have changed prescribers more than six times. Unsurprisingly, the number of diagnoses that children and teens have picked up has also risen from an average of 3 to 3.7 with some children having quite a large number of psychiatric diagnoses.

Alternative treatments

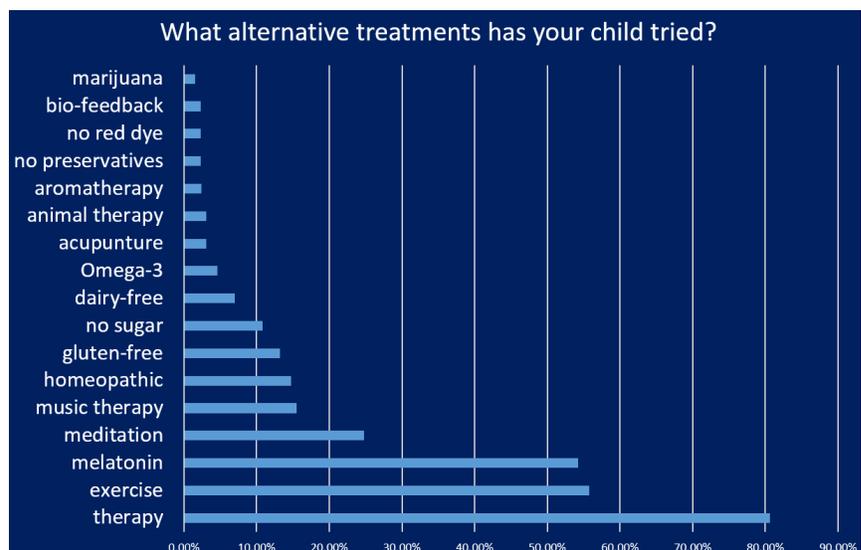
The vast majority of parents considered alternative methods of treatment important; after all, most parents wish for more choices in treatment for their child. 81% reported that their child had tried alternative treatments.

Only 8.5% of parents reported that they had not tried any alternative treatments, however that number is an increase from less than 4%

Only those with shared experiences really understood. Often the same people who loved and supported us were the ones who judged and thought our parenting was to blame."
-- a parent



"Even with years of thoughtful medical decisions, it is still a struggle and is likely to remain this way – it's the nature of the illnesses, medications and changing bodies." – the parent of a teen

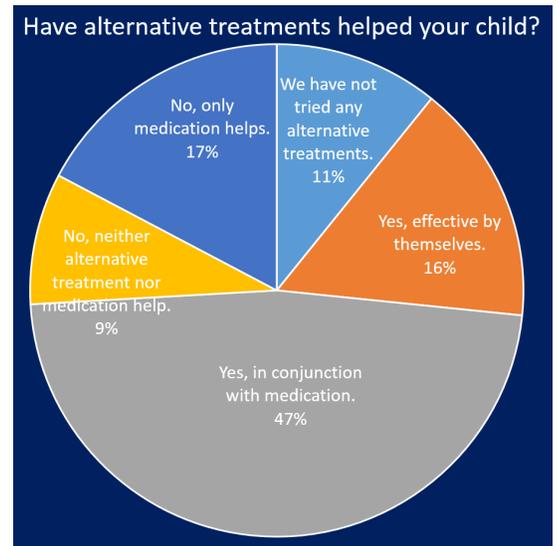


in 2006. The array of alternative treatments that parents have tried has also expanded and includes art and music therapy, meditation, acupuncture and animal therapy. The most often reported alternatives were therapy on its own (73%), exercise (56%), melatonin (50%), meditation (24%) or a change in diet. The number of parents who found alternative treatments effective has decreased. Only 16% of respondents found alternative treatments effective by themselves (44% in 2006); 48% believe that alternative treatments in conjunction with medication have been the most effective; 26% have found no help from alternative treatments (30% in 2006). Interestingly, in 2006 less than 4% reported they had not tried alternatives to medication and in 2016 that number had risen to 11%. One parent remarked, "There are many alternative treatments I would have liked to have tried, such as biofeedback, but they are not covered by our insurance."

Parent perspectives about medication

As in 2006, parents find medication to be an effective and necessary treatment for their children. 75% agreed that psychotropic medication improves their child's moods, focus or ability to function (74% in 2006). However, side effects continue to be a main concern of families. 76% of parents often worry about their child being over medicated or on medications that might have a dangerous impact or side effect. As one mother laments, *"It's so frustrating because these medications have such serious side effects, but my son does need medication. What do you do?"* Families continue to worry about the most serious side effects, yet felt, for the most part, that the exchange was worth it.

82% of parents agreed or strongly agreed that the process of finding medications or a combination of medications for their child was difficult and frustrating. Only 9% disagreed. Several parents reported that the stigma associated with medication creates additional challenges. As one parent put it, "There was precious little support or understanding." Many families commented that information about medication was essential and the internet was most helpful, followed by family organizations like PPAL and then their child's doctor. Many echoed one parent's comment: *"We need more information and it is difficult to find."* Repeatedly families pointed out that it was difficult to find accurate and appropriate information. Several others singled out insurance. One wrote, *"We are VERY dissatisfied with the fact that insurance, NOT MEDICAL PROFESSIONALS, are the only real decision-makers and they don't allow most of what actually works best."*



I'm more interested in the alternatives to medication than my child is...I wanted him to try these alternatives before the anti-anxiety medication for OCD, but he begged me for medicine because he felt out of control and believed medicine could help him. -- a mother

