



Tourette Association of America

Awareness. Research. Support.

2018 IMPACT SURVEY

**ASSESSING THE IMPACT OF TOURETTE SYNDROME
AND TIC DISORDERS ON INDIVIDUALS AND FAMILIES**

TOURETTE ASSOCIATION OF AMERICA



Table of Contents

Cover Page	0
2018 TAA Impact Survey Working Group.....	2
Survey Description	2
Responder Profile.....	2
Results	3
I. Diagnosis of Tourette Syndrome	3
II. General Impact.....	5
III. Tourette Syndrome and Education.....	8
IV. Medications	10
V. Comprehensive Behavioral Intervention for Tics (CBIT).....	11



2018 TAA Impact Survey Working Group:

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Description

The Tourette Association of America (TAA) conducted a web-based survey (January-May 2018), disseminated electronically to the Tourette Syndrome and Tic Disorder community via the TAA website, email, and social media. The survey was also distributed via email through the TAA's Centers of Excellence to affected individuals and families. Participants were informed that all data would be collected anonymously and would be used in aggregate by the Tourette Association of America (TAA) to communicate to the public and to policy-makers about the impact that Tourette Syndrome and Tic Disorders have on individuals and families. Participants had to be over 18 to take this survey. For those under 18, a parent or caregiver was required to fill out the survey on the child's behalf.

Responder Profile:

	Responses	
Adult with TS	29.77%	281
Adults replying on behalf of a child with TS	66.00%	623
Do not have TS/Tic Disorder*	4.24%	40
Total		944

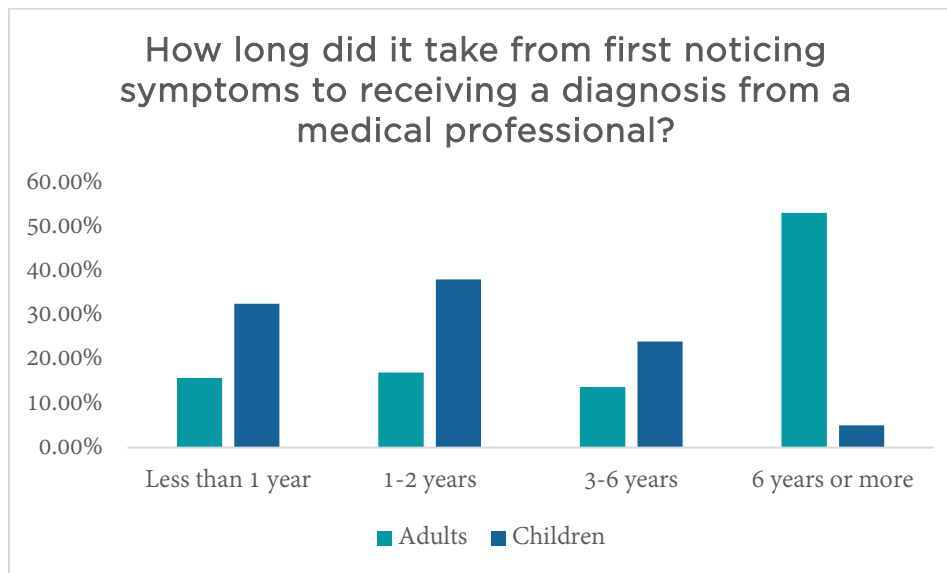
* Responders who noted that they "do not have TS/Tic Disorder" were routed to the end of the survey bypassing the questions below.



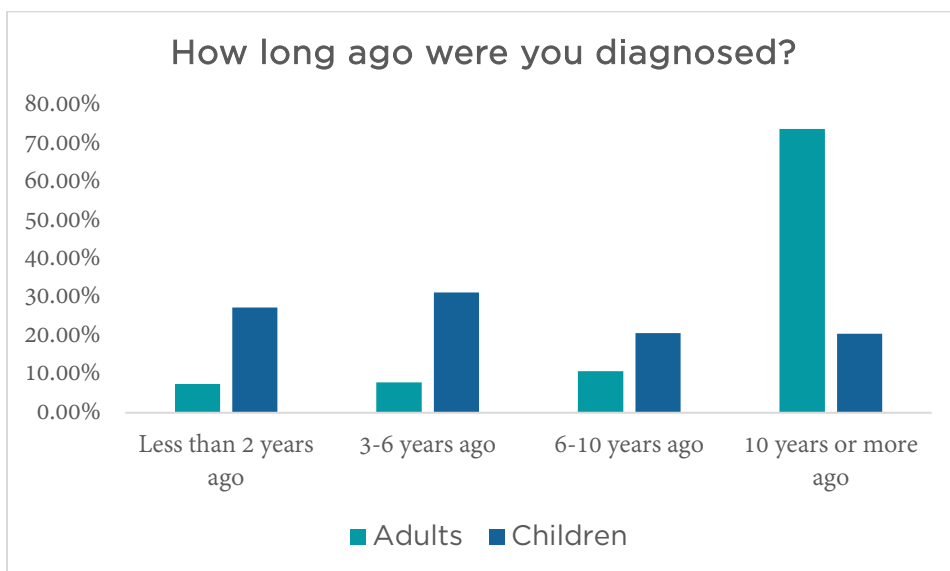
Results:

I. Diagnosis of Tourette Syndrome:

- ◆ The majority of children were diagnosed within 2 years of noticing symptoms, while many adults noted that diagnosis took 6 years or more.

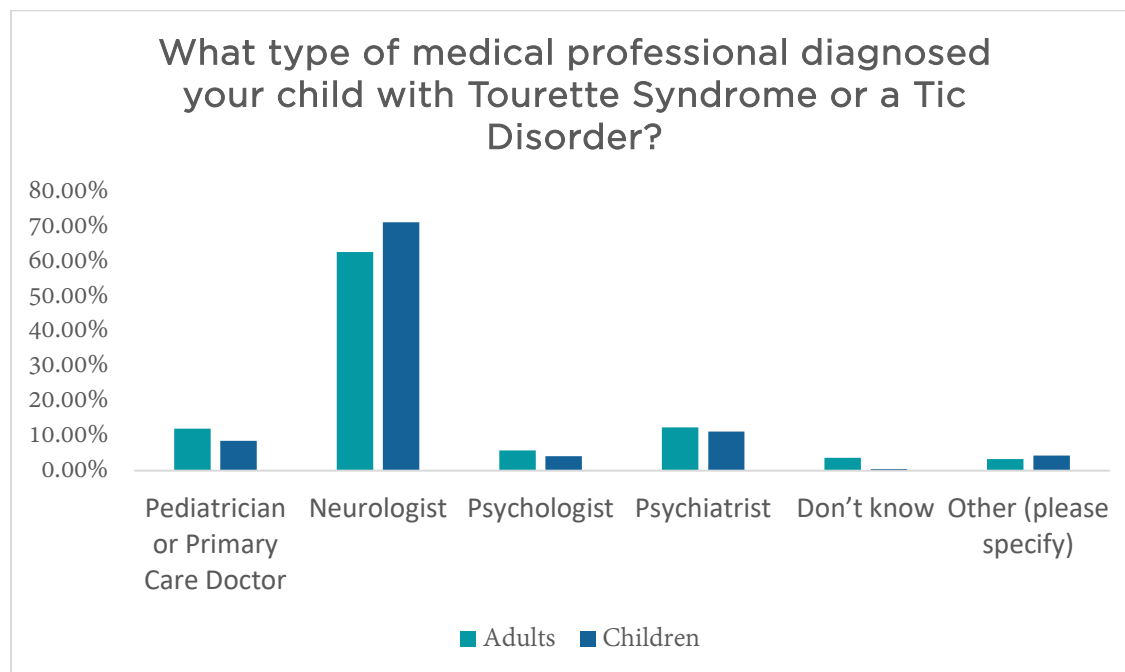


- ◆ The greater delay among adults may imply that trends in diagnosis were different a number of years ago, as 53% of adults noted they were diagnosed 10 years or more ago, while the majority of children were diagnosed more recently as indicated in the chart below:



Perhaps this decrease in the time to diagnosis can be attributed to efforts aimed at increasing awareness of Tourette Syndrome in the medical community and general population, although we recognize the inherent bias in conducting the survey among a population that is deeply connected to the Tourette community.

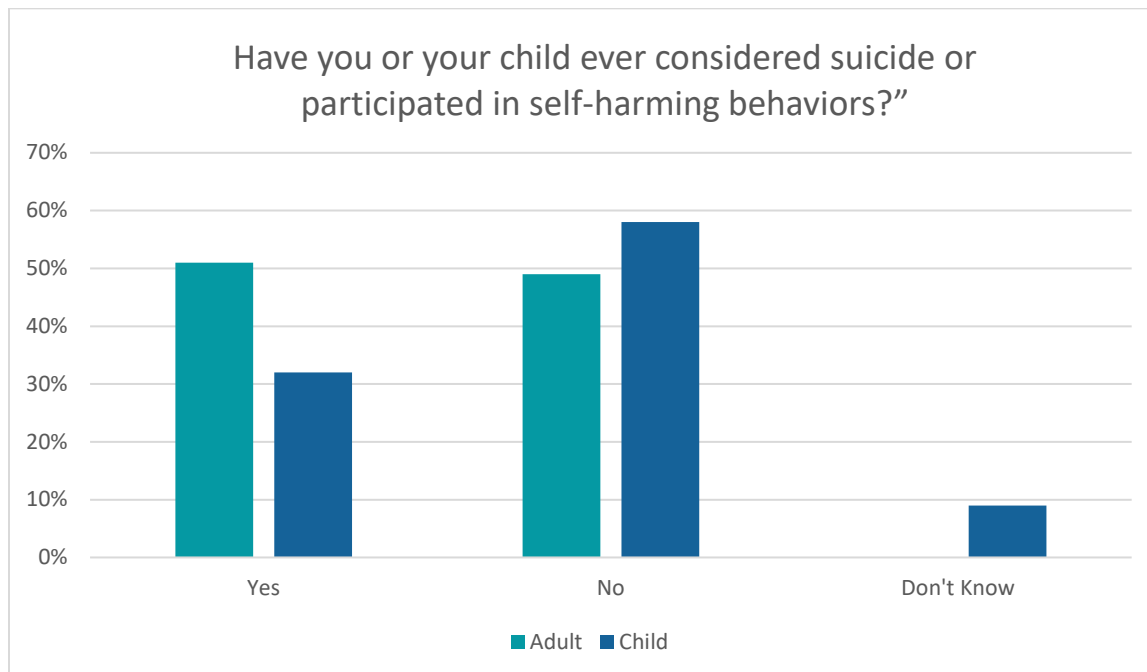
- ◆ Of note, neurologists were the most common diagnosing physicians for both children and adults



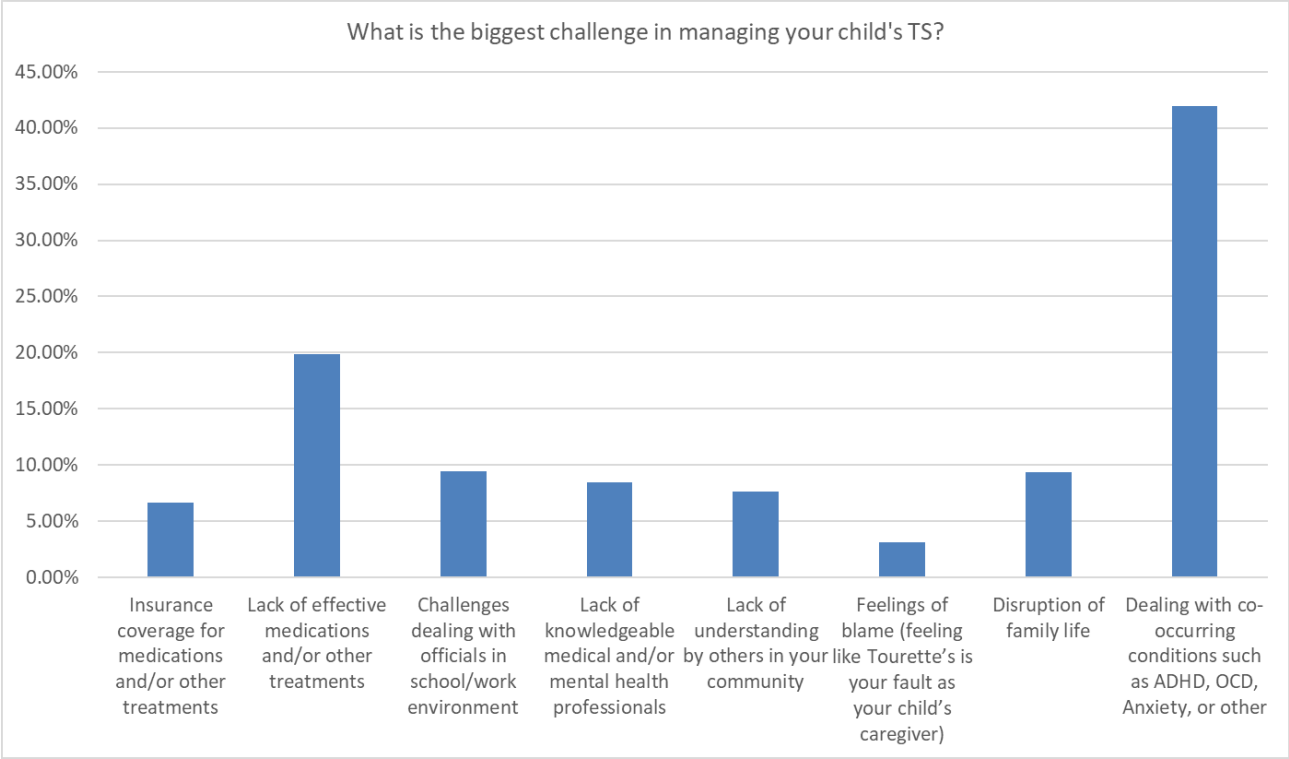


II. General Impact

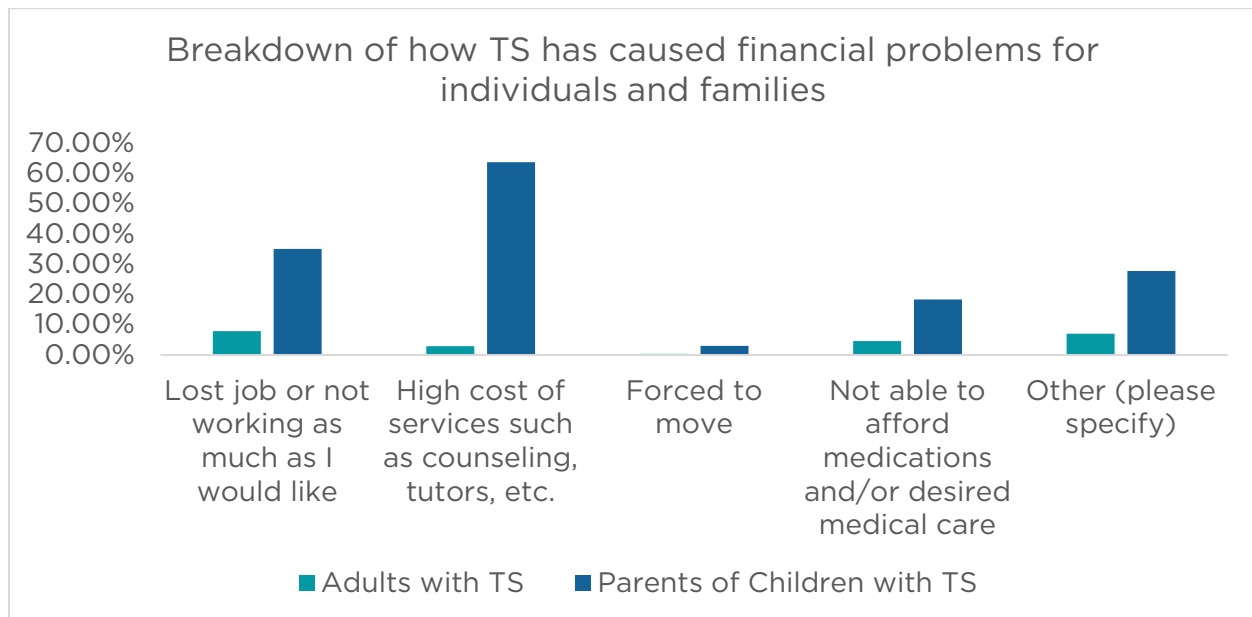
- ◆ **68%** of adults and **63%** of children (as reported by their parents/caregivers) said that they have felt discriminated against (for example, bullied, removals from class; suspensions; removal from extra-curricular activities such as sports, clubs, music, art; treated unfairly at work, etc.)
- ◆ **51%** of adults and **32%** of children (as reported by their parents/caregivers) reported considering suicide or participating in self-harming behaviors



- ◆ **36%** of adults and **42%** of children felt the biggest challenge in managing TS was dealing with co-occurring conditions. Both groups felt the second biggest challenge (23% adults and 20% of kids) was the lack of effective medications and/or other treatments.



- ◆ **15%** of adults and **43%** of parents of children with TS reported that managing TS caused financial problems for their family. A breakdown of the reasons for financial problems are listed in the chart below:

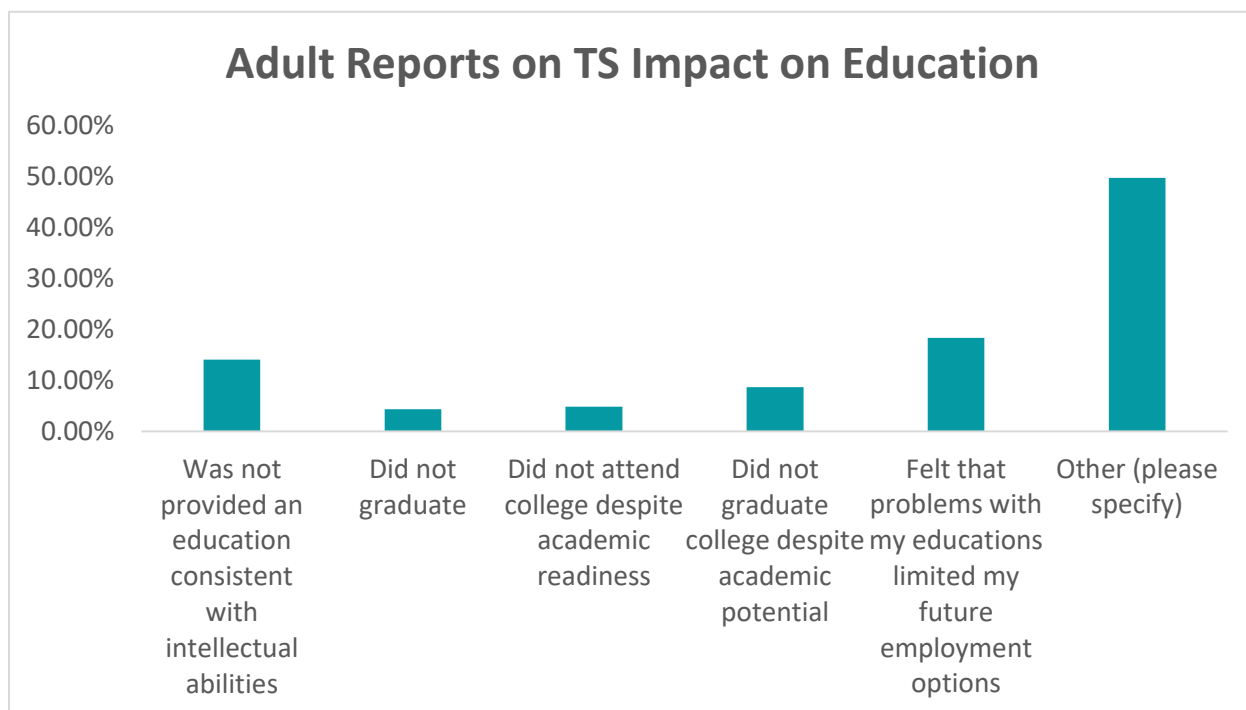


- ◆ **25%** of adults have reported having issues with substance use.
- ◆ **43.75%** of adults have stated that their Tourette Syndrome/Tic Disorder prevented them from forming meaningful friendships or romantic relationships.
- ◆ **27%** of adults and **18%** of children receive government healthcare such as Medicare, Medicaid, CHIP.
- ◆ **10%** of adults and **4%** of parents with children with TS receive Social Security Disability specific to their Tourette Syndrome, Tic Disorder, or related conditions.



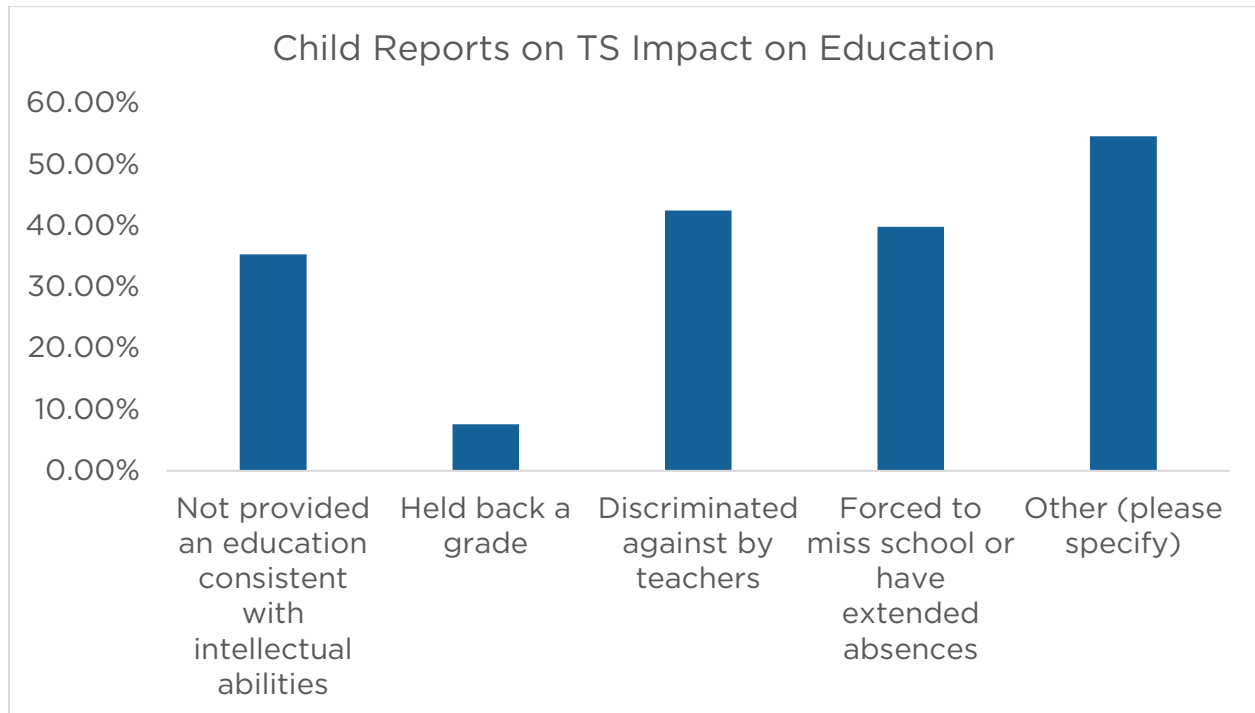
III. Tourette Syndrome and Education

- ◆ **76.7%** of adults and **83.4%** of children felt that Tourette Syndrome negatively impacted their school experience or education. Reasons for these feelings are noted in the charts below:



For Adults, the top 3 reasons noted within the “Other” category were:

1. Feeling bullied or teased, discriminated against or misunderstood (33.3% of “Other” category)
2. Not significantly affected or provided with the accommodations needed (25.3% of “Other” category)
3. Problems with focus, concentration, learning difficulties or other co-morbidities (17.2% of “Other” category)



For Children, the top 3 reasons noted in the “Other” category were:

1. Feeling bullied or teased, discriminated against or misunderstood (45.1% of “Other” category)
2. Issues with focus, concentration, learning difficulties or other co-morbidities (27.2% of “Other” category)
3. Not given access to accommodations or issues with school (17.5% of “Other” category)

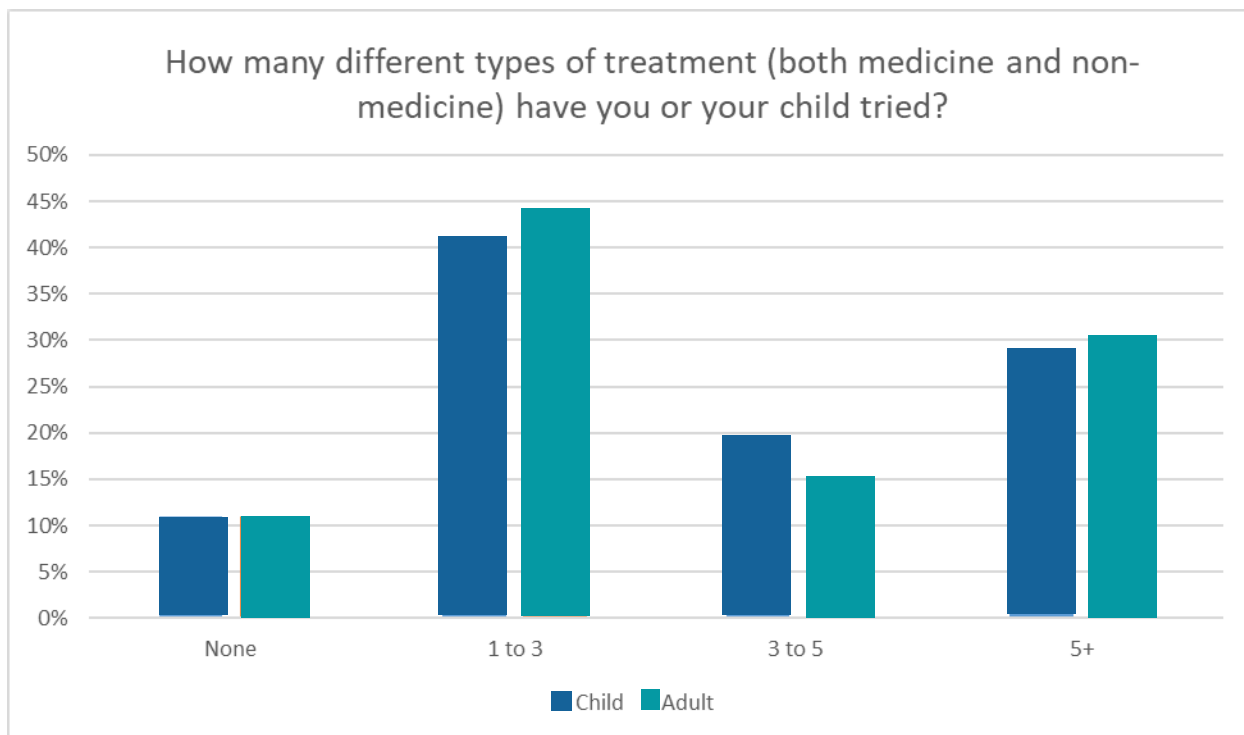
◆ **24%** of adults and **69%** of parents noted their child having or previously had an individualized educational plan (IEP) or 504 plan in place at their school.

◆ **49%** of adults noted that they have had to miss work or school due to their Tourette Syndrome/Tic Disorder or related conditions



IV. Medications

- ◆ **51%** of adults and **59%** of children take medications to help manage the symptoms associated with TS
- ◆ **30%** of adults and **29%** of kids have tried 5 or more medications at some point in their life.



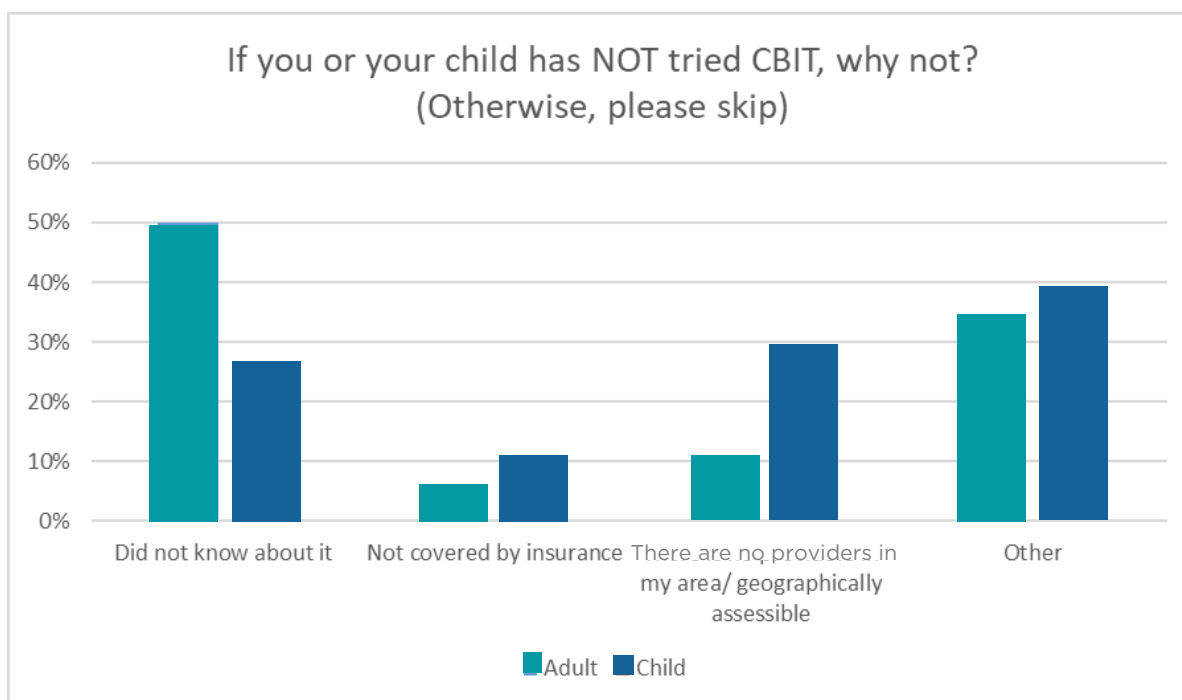
- ◆ **47%** of adults and **44%** of parents of children with TS do not feel that their symptoms are adequately controlled by existing medicine.



V. Comprehensive Behavioral Intervention for Tics (CBIT):

CBIT is a behavioral therapy that has been demonstrated to reduce tic severity. For more information, visit: <http://www.tourette.org/research-medical/cbit-overview/>

- ◆ **25%** of adults and **36%** of children with TS have tried CBIT.
- ◆ Of those who tried CBIT, **36%** of adults and **40%** of children found it helpful.



Responses in the "other" category included: their treatment provider did not offer CBIT as an option, simply not interested, skeptical about effectiveness, satisfied with other treatment strategies, in the process of trying CBIT now, financial reasons, had children who were too young or not ready to try the therapy, or some combination of the above. For adults, the most commonly cited "other" reason was that they were simply not interested (25% of responses in the "other" category); while for children, the most common reason was that tics were not currently their major problem (18% of the "other" category).



Like many medical conditions, Tourette Syndrome can have a significant impact on the children and adults who are affected as well as their friends and families. The TAA sincerely thanks each and every responder for taking the time to complete this survey. Your collective results are invaluable to us as we plan programming, research directions, education, and outreach initiatives to better serve the Tourette and Tic Disorder community and to ultimately improve the quality of life for those affected. Lastly, almost 500 of you shared your personal stories with us. We are so grateful for your openness and candor. We look forward to connecting with all of you.