

Impact Survey

Like many medical conditions, Tourette Syndrome can have a significant impact on children and adults, as well as their families and friends. At the TAA, we work to strengthen the bonds of our community by acknowledging challenges to be overcome, and celebrating the successes that happen when we work together.

CHILDREN/FAMILY STATS

43%

Of parents of children with TS reported that managing TS caused financial problems for their family.

42%

Of children felt that the biggest challenge in managing TS was dealing with co-occurring conditions.

83%

Of children felt that TS negatively impacts their school experience and education.

69%

Of parents noted their child having or having had an individualized educational plan (IEP) or 504 plan in place at their school.



FINANCIAL IMPACT

34%

Of parents report that they lost their job or they are not able to work as often due to increased caregiver duties of a child living with TS.

18%

Are not able to afford medications and/or desired medical care for their child.

63%

Struggle to cover high costs of services for their child such as counseling, appointments and tutoring.

4%

Of families were forced to move due to the financial impact of TS.

*The Financial Impact results represent a breakdown of the data reported in the Children/Family section.



CHILD OUTCOMES

63%

Of children have felt discriminated against.

32%

Of children have considered suicide or participated in self-harming behaviors.

40%

Of children were forced to miss school or have extended absences.



71%



Of children were diagnosed within 2 years of symptoms. Most adults were diagnosed after 10+ years. TS awareness efforts may be working but more is needed to decrease the time to diagnosis.



ADULT OUTCOMES

68%

Of adults have felt discriminated against.

51%

Of adults have considered suicide or participated in self-harming behaviors.

36%

Of adults have found one of the biggest challenges is dealing with co-occurring psychiatric disorders and symptoms.

Adults

15%

Of adults felt that managing TS caused financial problems for their families.

25%

Of adults have reported having issues with substance abuse.

44%

Of adults stated that TS prevented them from forming meaningful friendships or romantic relationships.

49%

Of adults noted that they have had to miss work or school due to their Tourette Syndrome or related conditions.



ADULT MEDICATION USE

51%

Of adults take prescription medications to manage symptoms of TS.

30%

Of adults have tried 5 or more medications at some point in their life.

47%

Of adults do not feel that their symptoms are adequately controlled by existing medicine.



CHILD MEDICATION USE

59%

Of children take prescription medications to manage symptoms of TS.

29%

Of children have tried 5 or more medications at some point in their life.

44%

Of parents do not feel that their child's symptoms are adequately controlled by existing medicine.



Impact Survey Disclaimer

The Tourette Association of America (TAA) conducted a web-based survey about the impact that Tourette Syndrome and Tic Disorders have on individuals and families. Approximately 1,000 responses were collected. Participants were required to be 18 years or older to take the survey. For those under 18, a parent or caregiver was required to fill out the survey on the child's behalf.