impact FOR TOURETTE'S

REPORT SUMMARY

Impact for Tourette's is a research project which highlights the challenges faced by children and adults with tic conditions, and their families.

About Impact for Tourette's

This first-ever Australian survey captured the perspectives of 206 respondents, including caregivers of children, adults with tics, and caregivers of adults.

Together with a series of in-depth healthcare experience interviews, this project identified the unmet needs of children and adults with tic conditions across seven key impact areas, pictured below.

Priority Areas for Change

Survey participants ranked the priority areas for change based on what they felt would most benefit Australians with tics:

1. **Improved recognition** of tic conditions as a disability
2. **Increased access to funding** for intervention and support
3. **Improved knowledge** among professionals, such as general practitioners and educators

This research is a powerful call for action, demonstrating the need for urgent change and greater support for those affected by tic conditions.

Key Impact Areas

June 2025

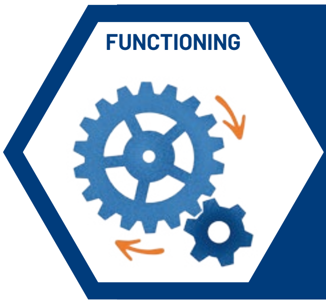
Key Findings

Limited access to healthcare services and intervention:

- **1 in 4 waited** over 2 years to receive a diagnosis;
- **minimal information** provided following diagnosis, with the Tourette Syndrome Association of Australia (TSAA) often one of the only available sources of information;
- **only 40%** reported positive experiences with services;
- **limited access to funding** for treatment.

Major impacts on daily activity:

- **two thirds** reported a moderate to extreme impact on their day-to-day life;
- over **80% experience tics daily**, often causing emotional distress and physical pain;
- **two thirds have sustained injuries** due to their tics;
- the most frequently reported impacts included difficulty concentrating and paying attention, learning, and sleeping.



"It makes him cry with exhaustion and exasperation. All he wants is a break from it." – Child Caregiver

Considerable challenges in education and employment:

- **75%+** reported a moderate to extreme impact on their education;
- key issues include difficulty completing work, pressure to suppress tics, and bullying;
- **three quarters of parents** reported teachers had very limited knowledge of tic conditions;
- half experienced **moderate to extreme impacts** on their employment;
- 1 in 10 adults **unable to work**.

Significant impacts on wellbeing:

- 1 in 4 adults and 1 in 10 children have **attempted suicide**;
- 1 in 3 experience **depression**;
- around **70% struggle with anxiety** disorders;
- nearly **80%of caregivers** also face mental health issues.

These findings show urgent action is needed to shape a better future for Australians living with tic conditions.

Key Recommendations

FINANCE

To address gaps in care for people with tic conditions and their families, the following **key recommendations** were developed in collaboration with the community:

- That government fund the **development of a National Clinical Guideline** for diagnosing and treating tic disorders for use by medical and allied health professionals.
- Allocate National Disability Insurance Scheme (NDIS) capacity building **funding to develop resources and training**, raising awareness and building understanding among:
    - Key government decision makers
    - General practitioners, psychologists and other healthcare professionals
    - Educators and school staff
    - Employers

> *"Improved education of medical professionals is essential to ensure accurate diagnosis, appropriate treatment, and effective management of tic disorders." – Child Caregiver*

INTERVENTION

- Adjust NDIS policy to **ensure accurate assessment and appropriate support** for individuals with tic disorders who have significantly reduced functional capacity.
- Include **targeted funding** in NDIS Foundational Supports for services supporting individuals with tic disorders and families.
- Targeted funding, beyond NDIS Foundational Supports, for **mental health and emotional well-being services.**

> *"The NDIS needs to include tic disorders for funding."*
> *- Adult with Tics*

- That State and Territory Departments of Education set **clear standards for supporting students** with tic disorders and ensure local school implementation.
- That major medical and research funding bodies, including the National Health and Medical Research Council and Medical Research Futures Fund, **invest in research for innovative treatments and care pathways**, potentially through a National Centre of Excellence in this field.

To read the full report visit
thekids.org.au/impactfortourettes

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