International Consensus Recommendations for the Identification and Treatment of TSC-Associated Neuropsychiatric Disorders (TAND)

Introduction

In 2023 the **TAND consortium** published international consensus recommendations to help with the identification and management of **TSC-Associated Neuropsychiatric Disorders (TAND)**. This is a short summary of the recommendations. The recommendations aim to empower individuals with TSC, their families, and the professionals that support them.

External Links

Click on, or scan, any of the following links:

- The consensus recommendations
- A short movie about the recommendations
- The TAND toolkit
- The TAND consortium

The main recommendations

The overarching recommendation is to '**screen, act, repeat**'.

SCREEN

Screening will ensure early identification of any potential concerns.

Given that all people with TSC are at risk for TAND, everyone with TSC should be screened at least once every year using checklists like the TAND-L (in a clinical interview) or TAND-SQ (self-reported, available on paper or using the TAND Toolkit App).

TAND Checklists

ACT

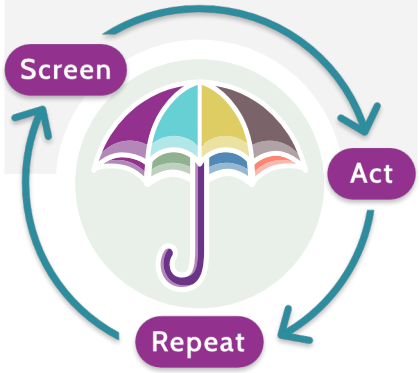
Don't wait and see hoping that things will get better on their own – act.

Once concerns have been identified, action should be taken. We recommend immediate intervention or support with the most appropriate biological (e.g. medications), psychological (e.g. talking treatments and supports) or social (e.g. financial, home, employment supports) for individuals with TSC and their families.

REPEAT

TAND changes over time and can emerge over time.

For this reason, screening and acting should be repeated on a regular basis to make sure that the right intervention and support is provided for the right things at the right time.



The Ten Core Principles

We identified ten core principles for identification and treatment of TAND that are important for all people with TSC. They are shown in the figure here.

1. **Everyone with TSC is at risk of TAND.**
2. **Everyone with TSC needs lifelong monitoring for the emergence of TAND.**
3. **Screen at least annually and follow up with appropriate action.**
4. **The goal is early identifcation and early intervention.**
5. **TAND clusters cluster together.**
6. **Always consider the impact of physical health problems and medications for physical health problems on TAND.**
7. **Work with families and caregivers as lived experts in TSC and TAND.**
8. **Generate a "bio-psycho-social" "whole-system" plan for intervention.**
9. **Be evidence-based and evidence-informed.**
10. **Strive for optimal functional outcomes and quality of life throughout the journey with TSC and TAND.**

Cluster recommendations

TAND is very common – almost all people with TSC will have some TAND difficulties at some point. To make it easier to navigate, TAND challenges can be grouped into eight TAND clusters. Here we present the key recommendations for each cluster.

Autism-like Cluster

- Autism is common in people with TSC and is associated with social-communication difficulties like absent or delayed onset of language to communicate, repeating words or phrases over and over again, poor eye contact, difficulties getting on with other people of similar age, doing the same thing over and over again, and being very rigid or inflexible about how to do things.
- Given that difficulties are often identified or diagnosed late, all individuals who show autism-like manifestations should be referred for a formal clinical evaluation for communication disorders and autism/autism spectrum disorder.
- Young children with autism and TSC may benefit from naturalistic developmental behavioural interventions while adults with TSC and autism-like cluster manifestations may benefit from autism interventions such as social skills support.
- Autism and the presence of often co-occurring physical health, neurodevelopmental, and mental health problems should be monitored throughout life and treated with evidence-informed treatments when required.

Mood/Anxiety Cluster

- Mood and anxiety problems (anxiety, depressed mood, extreme shyness or mood swings), are very common in TSC.
- Difficulties are often identified late or not at all. However, there are encouraging results of both non-pharmacological and pharmacological strategies.
- To ensure early detection and treatment, children and adults should be monitored.
- Extra efforts should be made to look for mood and anxiety symptoms in those with intellectual and other neurodevelopmental disabilities where manifestations of depressed mood or anxiety may be different (e.g. withdrawal from social interaction, loss of interest in previously enjoyed activities, anorexia, or increased dysregulated behaviours).
- Be aware that mood and anxiety symptoms may result as a consequence of underlying physical health problems or their treatments (e.g. seizures and anti-seizure medications, renal failure, or chronic pain).
- Because of individual differences in health and TAND manifestations, a personalised approach is recommended.

Scholastic Cluster

- Scholastic difficulties are common for those with TSC regardless of their intellectual abilities.
- Delayed onset of language development, difficulties in social communication, or other developmental milestones may predict scholastic diffi-culties in the future.
- Many school-aged children with TSC will likely benefit from additional support and should have ongoing screening and monitoring for scholastic difficulties in reading, writing, spelling and mathematics.
- All children with TSC should be considered for an individual educational plan (sometimes referred to as an 'IEP' or 'IEDP').
- Supportive/adaptive teaching strategies and appropriate accommodations (e.g. differentiated reading material, seat close to the educator, extra time, quiet spaces) should be considered in all educational settings.
- Planning for transitions through each stage of schooling and beyond secondary education should be done early.

Overactive/Impulsive Cluster

- Overactive and impulsive behaviours are common in TSC and both children and adults should be evaluated for them.
- In addition, all individuals with these behaviours should be considered for a clinical diagnostic assessment for ADHD.
- If ADHD is diagnosed, it can be treated through behavioural support or medication, as it would in the general population.
- Further research is needed to improve the understanding of over-activity, restlessness, and impulsivity in TSC.

Dysregulated Behaviour Cluster

- Difficulties with aggression, temper tantrums or self-injury are a serious burden to families who live with TSC.
- There can be many different reasons for dysregulated behaviour. It may originate from communication difficulties, impulsivity, anxiety, sensory sensitivity, demand avoidance, cognitive inflexibility, trauma, or pain.
- It can also be a result of the physical manifestations of TSC, such as growing SEGA, seizures, or an adverse effect of medications.
- There is no simple intervention or medication that can 'manage' dysregulated behaviour. General interventions like speech/language therapy work to support communication, cognitive- behavioural therapy work to support anxiety or inflexibility, and sensory strategies to support sensitivities might be useful.
- To understand problem behaviour, a thorough analysis should be conducted together with an evaluation of the intellectual and neuropsychological profile of the individual with TSC.
- Urgent physical examination is recommended for sudden onset or unexpected dysregulated behaviour. Medications should only be used after careful evaluation and always alongside a non-pharmacological (behavioural) intervention plan.

Eat/Sleep Cluster

- Little is known about eating difficulties (eating too much, too little or unusual things) in TSC. Eating difficulties can be linked to issues such as autism-related restricted eating, medication, ill-health or pain.
- There are no dietary supplements or special diets to improve TAND manifestations, e.g. the well-known ketogenic diet has mixed effects on TAND.
- Sleep difficulties (falling asleep or waking) are very common across all ages in TSC. It is difficult to distinguish 'cause' and 'consequence' in sleep problems and other TAND manifestations.
- Sleep difficulties may contribute to problems described in the other clusters in this summary, e.g. mood problems, on the other hand, sleep difficulties may result from other TAND manifestations, neurological manifestations, or adverse effects of medications.
- Sleep difficulties can also be related to access to electronic devices or caregiver contact upon waking. It is recommended to first identify and treat problems resulting from underlying health conditions or pain.
- Next, psychiatric causes of sleep problems should be examined and treated. Non-pharmacological strategies should always be used first (e.g. sleep education and sleep hygiene) before pharmacological strategies (e.g. melatonin or similar medications) are considered.
- Intervention plans for both eating or sleeping problems should always take the individual needs and profile of each person with TSC into account.

Neuropsychological Cluster

- About half of individuals with TSC have normal-range intellectual ability (with IQ>80) and 40-50% have intellectual disabilities.
- Neuropsychological deficits (e.g. in attentional, memory, or executive skills) can cause challenges in daily life activities like work or school, or in relationships.
- This is especially true for those with TSC that also have neurodevelopmental disorders like autism, attention deficit hyperactivity disorder (ADHD), or learning disorders.
- All individuals with TSC should receive a comprehensive assessment of their intellectual ability at the time of diagnosis and receive ongoing (at least annual) screening and monitoring for neuropsychological difficulties.
- Neuropsychological deficits can have a major impact on the functional ability of an individual and may present in various ways, such as anxiety, dysregulated behaviours, difficulties in education, or struggles in work.
- Coaching, training, or other non-pharmacological accommodations should be used to improve neuropsychological deficits.

Psychosocial Cluster

- TSC can have significant impact on the wellbeing of individuals affected by TSC as well as their families and caregivers.
- For the individual with TSC, psychosocial health and wellbeing should be monitored systematically including in the areas of self-esteem, family stress, relationship difficulties (e.g. with siblings or parents), and the ability to connect with others in the community or to progress in school, work or their career.
- Families and caregivers should also be assessed for their psychosocial needs and provided with integrated, coordinated care as needed.
- Support for improved quality of life for the individual with TSC and their caregivers is of critical importance.

About the TAND consortium and the TANDem-1 project

The TAND consortium is an international and multidisciplinary group of TSC researchers, clinicians and family representatives. The TANDem-1 project was a mobile-health project aimed at empowering families through the use of technology (a smartphone app) to reduce the TAND identification and treatment gap. As part of this project, practical recommendations for the identification and treatment of TAND were developed based on the 10 core principles listed above. This was done in a systematic way to generate up-to-date evidence-informed recommendations that can be used in all countries across the globe.

For more information about the **TAND consortium**, please see here. This summary was prepared by Katie Smith, Jan-Paul Wagenaar and the TAND consortium. September 2025