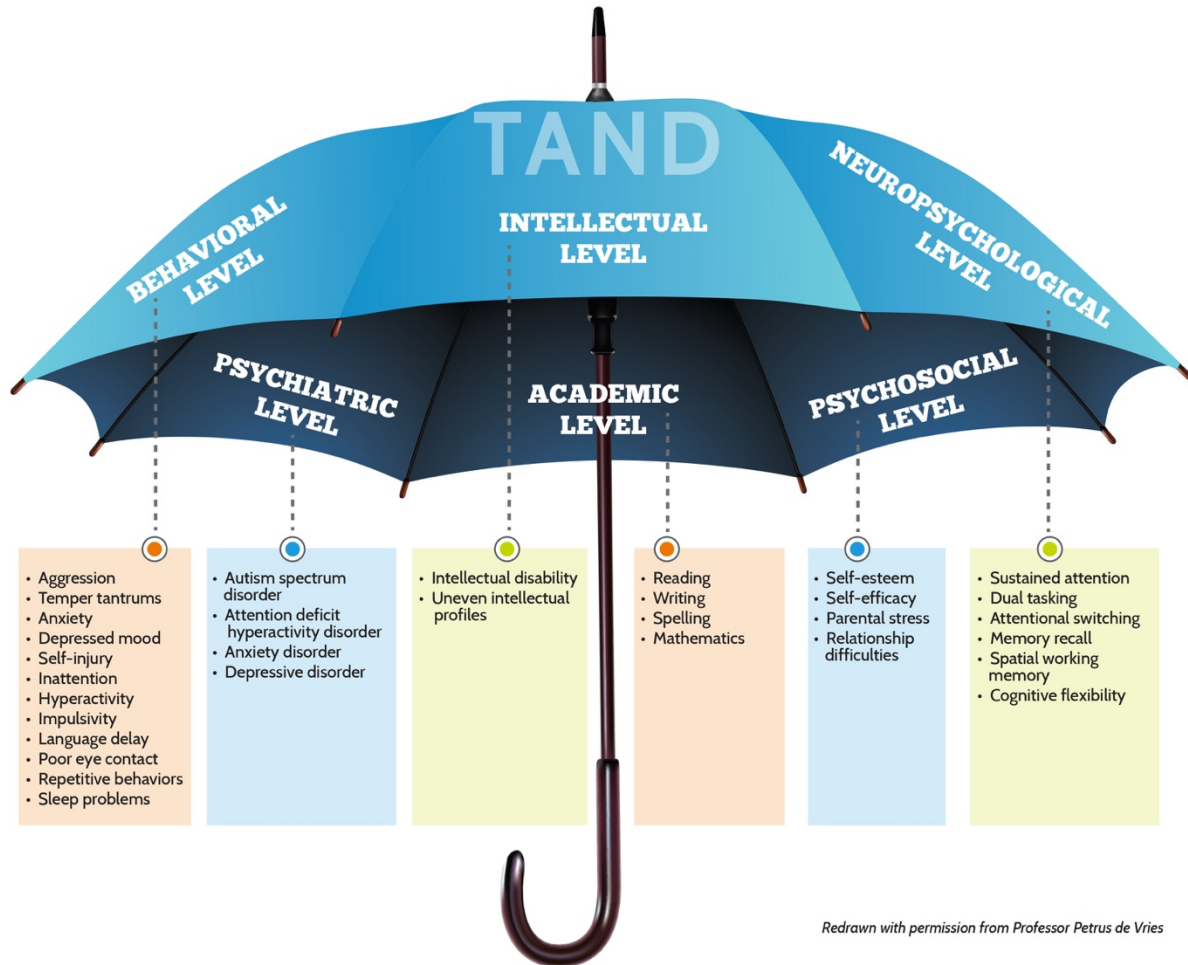


TSC-Associated Neuropsychiatric Disorders (TAND) and Education



Tuberous Sclerosis Alliance

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Dear Educators,

It is my pleasure to recommend *TSC-Associated Neuropsychiatric Disorders (TAND) and Education* as it is a vital, comprehensive resource for educators, school administrators and therapists working with individuals with TAND. As a child neurologist/neurodevelopmental disabilities specialist to hundreds of children with TAND, I remember the tears, consternation and frustration of children and parents without this coordinated collaboration. I also recall the relief of children and parents as they experienced the extraordinary success of coordinated collaboration with a well-informed school system. This publication is an invaluable tool for helping you achieve this success and ultimately academic progress in children with TAND.

As you read this publication, I advise paying close attention to the wide spectrum of difficulties these children face every day as well as the suggested evidenced-based strategies for intervention. Despite the differences in behavior type, the unifying aspect is they are not intentional. These behaviors are caused by tuberous sclerosis complex's alteration of the brain, which results in impact across the levels of TAND that include behavioral, psychiatric, intellectual, academic and neuropsychological. All of these concerns are compounded by psychosocial difficulties.

Although these challenges may be seemingly overwhelming in a busy school system, this publication provides the necessary knowledge and wisdom gleaned from research and Dena Hook's (author) more than 30 years' experience working with school systems. I *implore* you to read and utilize *TAND and Education* as it will not only support your success as educators for this population but also radically change the lives of affected children.

It is my privilege to give this publication my highest recommendation, and I look forward to many years of successful collaborations between empowered, well-informed educators, parents, children with TAND, the Tuberous Sclerosis Alliance and professionals within the TSC community.

Sincerely,

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Tuberous sclerosis complex (TSC) is associated with a range of neuropsychiatric disorders, which we refer to as TAND (TSC–Associated Neuropsychiatric Disorders).

Individuals with tuberous sclerosis complex (TSC) struggle in many areas but TSC-Associated Neuropsychiatric Disorders (TAND) can be the most impactful manifestation of TSC. Almost 90% will suffer from one or more of these disorders over their lifetime. It not only impacts their quality of life but also the area of education. Under the Individuals with Disabilities Education Act (IDEA) it states that when a behavior interferes with learning of the student or others around them a Behavior Intervention Plan (BIP) should be put in place. The first step in developing a BIP is to perform a Functional Behavior Assessment (FBA). When completing an FBA, it is imperative to understand the student’s disability and its manifestations. This publication has been developed to help school systems understand TAND and how it impacts the student’s education and functional skills in the classroom and in life.

As noted on the TAND umbrella on the cover of this publication, TAND impacts six areas:

1. Behavioral Level

- Aggression
- Temper Tantrums
- Anxiety
- Depressed Mood
- Self-Injury
- Inattention
- Hyperactivity
- Language Delay
- Poor Eye Contact
- Repetitive Behaviors
- Sleep Problems

2. Psychiatric Level

- Autism Spectrum Disorder
- Attention Deficit Hyperactivity Disorder
- Anxiety Disorder
- Depression Disorder

3. Intellectual Level

- Intellectual Disability
- Uneven Intellectual Profiles

4. Academic Levels

- Reading
- Writing
- Spelling
- Mathematics

5. Neuropsychological Level

- Sustained Attention
- Dual Tasking
- Attentional Switching
- Memory Recall
- Spatial Working Memory
- Cognitive Flexibility

6. Psychosocial Level

- Self-Esteem
- Self-Efficacy
- Parental Stress
- Relationship Difficulties

The purpose of this publication is to provide information about the TAND and offer strategies and suggestions to help school personnel cope with the complicated manifestations of TAND.

Behavioral Level

Many children with TSC have behavioral issues. The most recent surveys in children and adolescents with TSC confirm rates between 44-69% of social-communication difficulties (including poor eye contact, repetitive and ritualistic behaviors and speech and language delay), disruptive behaviors in 40-50% (including over activity, restlessness, impulsivity, aggressive outbursts, temper tantrums, and self-injurious behaviors) and mood-related difficulties (including depressed mood, anxiety, extreme shyness, and sleep disorders).

When you add learning disabilities and/or cognitive delays with these behaviors, individuals with TSC will need support and interventions in the school setting. Understanding and knowing the behavior is not intentional but is a manifestation of the student's disability will be key in developing an appropriate Individual Education Plan (IEP) that fits the needs of the student. Educating a student with TSC can be a challenging endeavor. But with the right support and understanding, families and schools can all be part of the solution by working together in making a difference for students with TSC.

Psychiatric Level

Individuals with TSC experience a higher rate of anxiety disorder than others. This anxiety can manifest itself into forms of excessive worrying, sporadic behavior, unexplained panic attacks, phobia, and separation anxiety. Students who have attended elementary school without problems

can suddenly develop school phobia in middle school. The effects of this disorder can be devastating and seem to be more challenging as the student gets older. An anxiety disorder can have a sudden onset because of one traumatic experience and can be something as simple as being embarrassed in front of their peers in the classroom. Students with TSC are more susceptible to anxiety disorder than the general population. What might be easily handled by a typical peer will be magnified in the mind of an individual with TSC and can sometimes develop into something as severe as “school phobia.”

Many times, because a student may have co-existing mental health conditions such as depression, he/she is misdiagnosed. Depression can mask the anxiety, or the anxiety can mask the depression. Other mental health issues such as aggression may be the result of the child having depression. Many individuals with TSC will develop Obsessive Compulsive Disorder (OCD). OCD is an anxiety disorder that causes unwanted thoughts and/or repetitive behaviors. Repetitive behaviors, such as hand washing, counting, checking, or cleaning, are done to control the unwanted thoughts to make them go away. These types of behaviors are sometimes called “rituals.” These rituals provide temporary relief but cause extreme anxiety when they cannot be performed.

When an individual is suffering from anxiety and/or mood disorders taking the position of “hard love” does not have the same outcome as a student without TSC. When you have a student with TSC it will take the school, medical health professionals, and families working together to develop an appropriate behavior intervention plan (BIP). A BIP plan for a student will be needed not only to support the student in school, but also to teach him or her how to deal with the anxiety issues and other aspects of their lives.

Unstructured situations are the most difficult for individual’s anxiety disorders. School assemblies, in the hallway between classes, or on the bus are all examples of unstructured situations that can produce anxiety for individuals with TSC. Extreme anxiety is very common and intensifies the stress, sometimes causing acting-out behaviors. If the school and family understand these constitute at-risk situations for students with TSC, they can put interventions in place to intervene before the behavior occurs.

Students with TSC may have high-functioning to severe Autistic Spectrum Disorder (ASD). Some individuals with TSC will not meet the criteria under the Individuals with Disability Education Act (IDEA) for Autism but still have many autistic-like tendencies (sensory processing issues, do not transition well, obsess about issues or items). Individuals who don’t meet the criteria of ASD can have more problems in life and school because they don’t quite “fit in.” It is important to have an IEP in place for these individuals. Qualifying them under “Other Health Impaired” in IDEA and developing an IEP can help ensure success in the classroom. IDEA stresses not only academic success, but it also stresses functional success as well for a student to receive a Free Appropriate Public Education (FAPE). It will take everyone to make sure an individual with TSC can develop the strategies needed to become independent and self-sufficient no matter the severity of their TAND.

Some behavior manifestations of ASD include:

- An inability to connect with others

- Language skills are poor or non-existent
- Issues with sensory processing (sensitive to light, textures, and noise)
- Self-stimulation
- Does not transition well
- Obsessive compulsive behaviors
- Repetitive speech

Individuals with TSC may exhibit frustration to communicate a need or feeling. This may be especially true for individuals who do not have any form of speech with which they can communicate with others. Coping with stressful events or activities may also cause individuals to feel anxious or frustrated, in other words they may feel overloaded by the stimulation around them.

These behaviors can serve as indicators of a person with sensory overload. Early intervention by a teacher or parent can reduce the risk of an overload. First, determine the function of behavior and then apply the appropriate intervention. Work with the student to develop appropriate ways to express frustration and develop coping strategies or ways to communicate a need. Parents and teachers can utilize preventive strategies to promote self-awareness, self-calming, and self-management. Developing a BIP in the IEP will help everyone on the team understand the student's needs and ensure everyone is on the same page with interventions at school and at home.

Attention Deficit Hyperactive Disorder (ADHD) with and without hyperactivity is very common in individuals with TSC. Students with TSC and ADHD have trouble paying attention, have impulsive behaviors (will act without thinking about what the result will be) and in some cases are overly active. ADHD often accompanies epilepsy and intellectual disability, and many children with autistic spectrum disorders will have problems with inattention, hyperactivity and/or impulsivity. ADHD is more common in individuals with TSC than the regular population.

Symptoms of ADHD:

- Unable to follow more than one-step directions
- Unable to process questions asked (starts listening but then looks around or fidgets and becomes lost when asked a question)
- Unable to listen (starts listening but then looks around or fidgets and seems lost when attention is returned)
- Unable to wait his/her turn to enter a conversation appropriately
- Unable to share and take turns when playing games
- Unable to respond to teasing and to resist dares (temptations)
- Unable to take responsibility for his/her actions or take criticism
- Unable to show interest in other's feelings
- Unable to understand other people's space or boundaries

Because of their behavioral manifestations, individuals with TSC struggle with social relationships not only as children without proper interventions and strategies, they will also struggle throughout

adulthood. They will be unable to develop and maintain successful relationships with both friends and spouses.

Understanding these behavioral manifestations are not intentional will be the first step to supporting individuals with TSC. Because they do not always understand or read facial expressions and body language, they sometimes come off as blunt and unfeeling. Many teens will become defiant and are at high risk for alcohol and drug abuse. Many young adults treat drugs, alcohol and truancy as a way for them to “fit in.” All of this seems bleak and hopeless, but with the appropriate interventions and support at home and at school, individuals with TSC can become independent, successful adults.

Success in school will be the first step in the right direction. Because individuals seem to ignore or not hear requests or directions and are disorganized (forgetting homework, not bringing materials to class, or being late), many educators feel the behaviors are intentional and will reprimand with negative outcomes. Over time, individuals will become defiant, stubborn, and angry because they don't understand why they act the way they do. Some of these individuals can develop oppositional defiant disorder (ODD). Many may struggle with expressing their feelings and develop quick tempers and impulsive behaviors. Unstructured situations are the most difficult for these students.

Intellectual Level

Approximately 45% to 60% of individuals with TSC develop cognitive challenges (intellectual disabilities), although the degree of intellectual dysfunction ranges from very mild to severe.

Some children appear to develop normally until the onset of seizures, when their progress slows or they lose developmental milestones. Individuals whose seizures continue unchecked even after treatment (intractable seizures) have a higher likelihood of intellectual impairment. While most individuals with TSC who have intellectual disabilities also have epilepsy, many individuals with TSC who have seizures do not have significant intellectual disabilities.

Students with TSC may have uneven cognitive profiles. They can have fragmented skills showing great strengths in one area but severely absent or delayed in another area. Higher-functioning individuals with TSC can have trouble with basic skills and still excel in other areas. A school system cannot make assumptions based solely on a person's ability in one academic or functional area. It is important to assess the whole student when developing goals and behavior interventions plans on his or her IEP.

A consensus on the initial neuropsychological evaluation and subsequent follow-up published in 2005 (see last page of this publication) includes recommendations for an initial evaluation and follow-up neuropsychological testing at times of school transition and/or as needed based on the needs of the individual with TSC. A neuropsychological evaluation is the best form of data to have in identifying a student's baseline and needs. A typical school evaluation is performed to determine if the student qualifies for Special Education to support progressing in the general education curriculum. A neuropsychological evaluates specific cognitive abilities affected by the

TSC lesions (cortical tubers, subependymal nodules, and subependymal giant cell astrocytomas) in the brain. This type of evaluation provides valuable information about a student's development in areas such as language, memory, attention, perception, coordination, and personality – basically “how the child learns.”

Many parents of children with TSC are already working with a neuropsychologist and have current neuropsychological evaluations. It is in the school's best interest to utilize this information when developing a child's IEP. The recommendations on the neuropsychological evaluation will support the IEP Team in developing a plan that best fits the needs of the student.

Academic Level

A majority of students with TSC suffer from executive functioning issues. This can play a major role in failure in the classroom. Below is a list of executive functioning areas for which students with TSC will need support:

- Managing time
- Organizing thoughts and materials
- Paying attention
- Planning and prioritizing
- Getting started on an assignment
- Problem solving
- Self-reflection
- Managing emotions and impulses

When a student with TSC has brain involvement learning disabilities can occur. Students with TSC may be doing fine at the beginning of the school year and start struggling in the middle or end of the school year depending on their seizures, tumor growth, and the area of the brain where the tumor or seizure are located. Please note you might have to develop a new IEP more than once during a school year depending on what is going on medically with the student. Behaviors and learning issues are a red flag for changes in tumor growth and seizure activities in the brain.

Below are some learning disabilities that can affect students with TSC.

Dyslexia

According to the U.S. National Institutes of Health, dyslexia is a learning disability that can hinder a person's ability to read, write, spell, and sometimes speak. The area of the brain that controls the ability to translate images received from the eyes or ears into understandable language may be affected. The child's vision or hearing ability has nothing to do with their learning difficulties.

Warning signs of dyslexia:

- Trouble moving to the rhythm of music
- Cannot remember content of stories
- Does not understand left from right

- Trouble with visual spatial concepts
- Uncoordinated (skipping is difficult)
- When speaking, may use wrong word or reverse words
- When writing reverse letters, words, and/or numbers
- Cannot proof their own written work
- Does not understand time
- Does not understand seasons

Dyscalculia

When a child has TSC, involvement in the language and visual processing centers of the brain dyscalculia can result. Dyscalculia is an inability to understand the meaning of numbers and/or inability to apply math principles to solve problems.

Warning signs of dyscalculia:

- Does not understand numbers and their quantities
- Does not understand addition
- Does not understand subtraction
- Does not understand multiplication
- Does not understand division
- Does not understand abstract concept (algebra)
- Has difficulty in making change and handling money
- Does not recognize patterns
- Does not understand days, weeks, months
- Does not understand time
- Has difficulty lining numbers up on a page
- Telling time

Dysgraphia

Dysgraphia is a learning disability that affects written expression and difficulty in processing the spoken language. Students with dysgraphia have visual-spatial difficulties and struggle organizing letters, number and words on a line or page. They can also have language processing difficulty. It may take a child with language processing 10 seconds or more to interpret what is being asked of them.

Warning signs of dysgraphia:

- Trouble writing or forming letter shapes
- Is not consistent with spacing between words and letters
- Tires of writing even short assignments
- Refuses or is reluctant to do writing assignments
- Does not like to draw or color
- Awkward pencil grip and unnecessary pressure on pencil point
- Cannot stay on the line when using scissors to cut
- Older students may struggle getting thoughts down on paper

Neuropsychological Level

Many students with TSC will struggle with:

- *Sustained Attention*: Being able to direct their focus on the completion of a task. Distractions of any kind can break their attention and make it difficult for them to complete a task in a timely manner.
- *Dual Tasking*: Being able to perform two tasks at the same time.
- *Attention Switching*: Changing from one activity to another without a transition.
- *Memory Recall*: Retrieving information from the past along with encoding and storage.
- *Spatial Working Memory*: Keeping information long enough to complete complex assignments.
- *Cognitive Flexibility*: The ability to think about multiple concepts simultaneously.

Psychosocial Level

Students with TSC can experience low self-esteem. Because a high number of students with TSC will have learning and attentions issues and will experience little or inconsistent success, low self-esteem is common. When you add skin manifestations such as angiofibromas (facial tumors), they can be the target of bullying and cruel jokes. Low self-esteem can increase the risk of anxiety and depression sometimes leading to avoidance behaviors (acting out) and even “school phobia.”

It is believed self-efficacy is needed to influence the ability for a student to face challenges positively and to make positive choices in any given situation. Self-efficacy is built through success in school performances, experiences with peers, belief in oneself, persuasion (verbal and otherwise), and positive self-judgment. It is important to build self-efficacy in students with TSC because they will be dealing with health and social challenges throughout their lives. Supporting students with TSC to develop social and emotional strategies on their IEP will provide them with the resources they need to transition into adult life.

Students with TSC struggle in the area of relationships with their peers. Helping them to develop positive strategies in social situations can help them become more successful as they transition to the adult world. Social goals should be addressed on a student’s IEP. The Individuals with Disabilities Education Act (IDEA) not only requires academic goals on an IEP but also functional goals. Social skills would be considered a functional skill in both education and life in general. As a teacher, your relationship with a student with TSC needs to be a relationship of trust and understanding. Following these strategies can build the level of trust with a student:

- Be very specific in what you are asking the student to do. Do not use subjective language.
- Let the student know he/she can count on you not to put him/her in an embarrassing situation. (For instance, asking him/her to perform a task in front of the class he/she is not good at doing.)
- Write directions on the board, verbally go over directions, and give an example.
- Make sure classroom rules are understood and posted visually within the classroom.

These simple strategies will build a positive relationship with a student and increase the ability to have a positive school experience.

A teacher's relationship with parents of students with TSC is just as important as the relationship with a student. TSC is a very complicated disorder and can change very quickly. Know that parents of students with TSC are experts in their child's disorder. They have become medical students, pharmacists, researchers, and educators out of necessity. Parents of a child with TSC never knows from one day to the next what will be thrown their way. Seizures, heart issues, lung issues, brain surgery, and medication changes are just a few of the issues families of a child with TSC deal with on a day-to-day basis. Parental stress is a constant in the life. When you are struggling with parents, please remember what is going on in their lives and try to be empathetic and work with them.

The TS Alliance is dedicated to making sure school systems have what they need to understand TSC. We are here to support you and provide the necessary support for all school district personnel from the teacher to the school nurse.

- *TSC 101 Training*: This training is for school personnel to understand the complexities of TSC and education
- *Education Mentor Program*: The Educator Mentor Program (EMP) was developed to support school systems in understanding the learning needs of children with TSC. The EMP is comprised of administrators, therapists, physiologists, and teachers from pre-kindergarten to college level having experience with TSC. -They provide one-on-one (phone, e-mail, text, Facetime) support to any professional in the school system needing education and support in understanding the educational complexities of TSC and a sounding board when developing classroom interventions.
- *Education Parent Mentor Program*: A Parent Educational Mentor (EPM) has experience working with school systems in understanding TSC. EPMs support parents/caregivers to become partners with the school system in their child's education. They can attend a school meeting (in person, SKYPE, Go to Meetings, Facetime) to give support to both the parent and school district by providing the school system and parents with TS Alliance support resources.
- *Publications Dealing with TSC and Education*: To access our publications and learn more about TSC, visit www.tsalliance.org/individuals-families/school-issues/.

For more information on these resources and programs contact Dena Hook, Vice President of Support Services, at dhook@tsalliance.org or 1-800-225-6872 Ext 215.

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deVries, PJ (2014) *The TAND Checklist Lifetime version (TAND-L)*

deVries, PJ (2014) *Consensus Clinical Guidelines for Assessment of TAND*

Consensus clinical guidelines for the assessment of TSC-Associated Neuropsychiatric Disorders (TAND) All individuals with TSC should be screened for TAND at least annually and more detailed evaluations should follow from screening. In addition, all individuals with TSC should have a comprehensive formal evaluation at key developmental timepoints as outlined below in this table (de Vries et al., 2005; Krueger et al., 2013).

STAGE	AGE RANGE	GENERAL PURPOSE OF ASSESSMENT	GENERAL AREAS TO ASSESS	AREAS OF PARTICULAR CONCERN IN TSC	BEHAVIORAL, PSYCHIATRIC, AND ACADEMIC DISORDERS OF PARTICULAR CONCERN IN TSC
At diagnosis		Initial assessment of cognitive and behavioral profile	As listed for chronological age		
Infancy	Birth - 12 mos	To perform a baseline assessment for regular monitoring of development	Global standardized assessment of infant development	Impact of seizure onset and treatment on development	
Toddler	1y - 2y11m	To identify early developmental disorders Specific skills: <ul style="list-style-type: none"> • Gross and fine motor skills • Social-communication skills 	Global intellectual ability and adaptive behaviors	Quality of eye contact, joint attention, reciprocity	Autism and autism spectrum disorders (ASD) Severe aggressive outbursts Severe sleep problems
Pre-school	3 y to school entry	Evaluation of cognitive and behavioral profile to ensure the provision of appropriate educational programs	Global intellectual ability Specific neuropsychological skills: <ul style="list-style-type: none"> • Receptive and expressive language • Social-communication skills • Attentional and executive skills • Visuospatial skills • Motor skills 	Uneven profile of abilities Poor expressive language Poor reciprocity, peer interaction Poor regulation of affect and impulse Poor bilateral coordination	Autism and ASD ADHD and related disorders Self-injurious behavior
Early school years	6y-8y	Monitoring the child's ability to make appropriate educational progress	Global intellectual abilities Specific neuropsychological skills: <ul style="list-style-type: none"> • Receptive and expressive language • Social-communication skills • Memory • Attentional and executive skills • Visuospatial skills • Motor skills 	Best time to establish baseline to assess whether specific cognitive skills and academic performance are discrepant from global intellectual abilities Poor expressive language and word retrieval Rote learning difficulties Selective attention, sustained attention difficulties	Academic difficulties (reading, writing, spelling, mathematics) ADHD and related disorders Peer problems Aggressive behaviors

The consensus clinical guidelines for the assessment of TAND (continued)

STAGE	AGE RANGE	GENERAL PURPOSE OF ASSESSMENT	GENERAL AREAS TO ASSESS	AREAS OF PARTICULAR CONCERN IN TSC	BEHAVIORAL, PSYCHIATRIC, AND ACADEMIC DISORDERS OF PARTICULAR CONCERN IN TSC
Middle school years	9y-12y	Comprehensive review of child's abilities, specific learning difficulties, and behavioral problems in preparation for transition to secondary education	Global intellectual abilities Specific neuropsychological skills: <ul style="list-style-type: none"> • Receptive and expressive language • Social-communication skills • Memory skills • Attentional and executive skills 	Subtle deficits of social communication, unusual interests Poor working memory, episodic memory Planning, organizational abilities, multi-tasking difficulties	High functioning ASD/Asperger's Peer problems Academic difficulties (reading, writing, spelling, mathematics)
Adolescence	13y-16y	Determining individual needs and the support required for transition into adulthood	Global intellectual abilities Specific neuropsychological skills: <ul style="list-style-type: none"> • Attentional and executive skills • Vocational assessment with knowledge of cognitive strengths and weaknesses • Adaptive behavior and daily living skills 	Poor judgement, decision-making	Depressive disorders Anxiety disorders Peer problems Epilepsy-related psychotic disorders
Adults	18y+	Newly diagnosed adults: Assessment of cognitive, behavioral and vocational profile, determining bio-psycho-social needs	Global intellectual abilities Specific neuropsychological skills: <ul style="list-style-type: none"> • Attentional and executive skills • Memory skills 	Difficulty with integrational skills Working memory, episodic memory problems	Depressive disorders Anxiety disorders Epilepsy-related psychotic disorders
Adults (follow-up)	18y+	Monitoring for emergence of psychiatric problems or changes in existing cognitive and behavioral profile	Dependent adults: <ul style="list-style-type: none"> • Annual review of social care needs and support Independent adults: <ul style="list-style-type: none"> • Vocational advice • Genetic counseling as appropriate • Review if problems arise 	Pay particular attention to change in cognitive abilities or behavior Pay particular attention to change in cognitive abilities, vocational performance and behavior	Depressive disorders Anxiety disorders Epilepsy-related psychotic disorders

The table shows the time points recommended for evaluation and the goals of evaluation and lists specific areas of concern for each age group. Table reproduced with permission from de Vries et al. (2005) updated by de Vries 2014. Note: Many features listed in these columns can present at any age, but are listed here at stages most commonly associated with the emergence of such difficulties in TSC.