Behavioral Issues and Tuberous Sclerosis Complex
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety and Mood Disorders and TSC</td>
<td>3</td>
</tr>
<tr>
<td>Attention Deficit Hyperactivity Disorder (ADHD) and TSC</td>
<td>4</td>
</tr>
<tr>
<td>Autism Spectrum Disorder (ASD) and TSC</td>
<td>9</td>
</tr>
<tr>
<td>How Do I Get the School to Work with Me?</td>
<td>12</td>
</tr>
<tr>
<td>Functional Behavior Assessment</td>
<td>15</td>
</tr>
<tr>
<td>Behavior Intervention Plans</td>
<td>16</td>
</tr>
<tr>
<td>When Behaviors Interfere with School Policy</td>
<td>17</td>
</tr>
<tr>
<td>Sample Letter</td>
<td>20</td>
</tr>
<tr>
<td>IDEA Behavior Policy Chart</td>
<td>21</td>
</tr>
<tr>
<td>Resources</td>
<td>22</td>
</tr>
<tr>
<td>References</td>
<td>24</td>
</tr>
<tr>
<td>Consensus Clinical Guidelines for the Assessment of TSC-Associated Neuropsychiatric Disorders (TAND)</td>
<td>25</td>
</tr>
<tr>
<td>TAND Checklist</td>
<td>27</td>
</tr>
</tbody>
</table>
Behavioral Issues and Tuberous Sclerosis Complex

Many children with tuberous sclerosis complex (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) as well as mood-related difficulties (including depressed mood, anxiety, extreme shyness) and sleep problems in 20-50%.

When you couple learning disabilities and/or cognitive delays with these behaviors, it is clear that individuals with TSC need support and interventions not only at home but also in the school setting. Understanding and knowing that the behavior is not intentional but is a manifestation of the individual’s disability is imperative for the individual’s success in school and life.

The purpose of this publication is to provide information about the behavioral issues in TSC and offer strategies and suggestions to help individuals, school personnel, and parents cope with these behaviors. The psychological and behavioral issues in TSC are very important and complicated issues which need to be understood by families, educators, and policy makers. There is a lot to learn and that takes time. However, we are not alone in the frustration or in being unsure of how to handle the behaviors. We can all be part of the solution by working together in making a difference for children with TSC.

Resources in understanding behaviors and behavior strategies and school/family partnerships are provided on page 22.

Anxiety, Mood Disorders and TSC

Individuals with TSC experience a higher rate of anxiety disorder than others. This anxiety can manifest itself into forms of excessive worrying, sporadic behavior, and unexplained panic attacks. 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. It can be something as simple as being embarrassed in front of peers in the classroom. Children with TSC are more susceptible to anxiety disorder. What
might be easily handled by a typical peer will be magnified in the mind of an individual with TSC to the point of developing 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 in an effort to make them go away. These types of behaviors are sometimes called “rituals.” These rituals provide temporary relief, but cause extreme anxiety when they can not be performed.

When an individual is suffering from anxiety and mood disorders taking the position of “hard love” does not work. When you are dealing with school-age children, it will take the school, medical health professionals, and families working together to develop an appropriate behavior modification plan. A behavior modification plan for the child 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 on the other aspects of their lives.

Unstructured situations are the most difficult for individuals with mood and 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 for individuals with TSC and intensifies the stress, sometimes causing acting-out behaviors. If the school and families understand that these are at-risk situations for students with TSC, they can put interventions in place to intervene before the behavior occurs.

**Attention Deficit Hyperactive Disorder (ADHD) and TSC**

To understand the difference between behaviors associated with ADHD and intentional or attention-seeking behaviors, let’s look at some of the common behavior manifestations 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

Even though a lot of these characteristics are very typical in many children, ADHD children seem to be at least two to three years or more behind their peers in maturity levels. (An individual 14 years old will act like a child who is 10 years old.)

Because of their behavioral manifestations, individuals with TSC struggle with social relationships not only as children, but 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 that these behavioral manifestations are not intentional will be the first step to supporting individuals with ADHD. Because they do not understand or read facial expressions and body language, they sometimes come off as blunt and unfeeling. Many teens with ADHD will become defiant and are at high risk for alcohol and drug abuse. Many young adults treat drugs, alcohol, and truancy as a ways for them to “fit in.” Parents of children with ADHD must be aware of this risk and do proactive planning and education. All of this seems bleak and hopeless, but with the appropriate interventions and support both at home and at school, individuals with ADHD can become independent, successful adults.

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

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

The best way for the school and parents to work together is getting the school system to recognize the disability of ADHD. A child with TSC who has ADHD that is adversely affecting their education needs to be evaluated under the Individuals with Disabilities Education Act of 2004 (IDEA). The disability of ADHD is not one of the 12 categories listed under IDEA. To have your child evaluated under IDEA, the parent or guardian would request an evaluation not under ADHD but under “Other Health Impaired.” An Individual Education Plan needs to be developed when a child is identified as having a disability that adversely impacts learning. The chapter, entitled “How Do I Get the School to Work with Me,” outlines this process. Once a student has been identified as having a disability under IDEA, an IEP will be written. Parents are a very important member of the team that develops the IEP. (See: TS Alliance publication “What is an IEP?”)

There will be specifically designed interventions to support the individual in being successful in the classroom. By having an IEP in place, educators will be required by law to provide the supports needed for the student to succeed. Because behaviors often become more severe as the individual grows older, it is important to get an IEP in place as early as possible in a child’s school career. It takes everyone to make sure an individual with ADHD develops the strategies needed to become independent and self-sufficient. To do this, the IEP team must focus on the positive aspects of the individual. These individuals tend to be creative, artistic, and believe it or not, anxious to please.

When an individual knows from day to day what is expected, it is easier to be prepared for the day. Making sure a daily schedule is followed will help him/her succeed in school. He/she will know what behavior and responsibilities are expected and will build confidence through being successful. Please understand this will not happen overnight; it requires consistency and follow-through, not only by the student, but also by the adults implementing the formal plan. There will need to be numerous modes of input in the implementation of the schedule.

- The schedule will need to be placed where the student can see it daily.
- The schedule will need to be gone over verbally so the student not only sees it but also hears it.
- There will need to be numerous reminders of the schedule throughout the day.
This also needs to happen at home. Post the homework schedule on the refrigerator and remind the child when it is time to do homework, where homework goes after it is done, and where the backpack goes after he or she puts the homework in it. Then, of course, remind him/her to take it to school when leaving. This may seem like “over kill,” but it will take a long time for the child to develop the ability to automatically follow the schedule.

If the student’s schedule is going to be changed in any way, either at home or at school, the student will need to be prepared for the changes. Transition is very difficult for children with ADHD and anxiety disorders. However, with proper preparation the student will eventually help develop the ability to handle transitions with fewer difficulties.

Consistency and follow-through will mean failure or success for individuals with ADHD. Parents sometimes will not be consistent in discipline – what is okay one day will not be okay the next. Parents must be prepared to follow through with a consequence and not sway from it. Do not apply a consequence you are not willing to follow through with such as, “You are grounded for a month.” If the parent does not follow through with this consequence then it sends a message the parent doesn’t mean what was said. Making sure the discipline matches the crime is essential, as is not overreacting because you are tired. Of course, that’s easier said than done. With children with ADHD, consistency is essential to learning appropriate behavior.

There is growing evidence to suggest that even in cases where the diagnostic criteria for ADHD are not met, children with TSC “can show specific attention deficits and impaired goal directed behavior associated with executive control processes” (de Vries et. al., p. 185). In terms of attention deficits in TSC, de Vries and Watson (2008) suggest that attention issues need to be viewed in a neurodevelopmental approach. If one stage in attention development is compromised for a child with TSC, then other stages will be affected in a sequential manner. Attentional skills should not be viewed as separate deficits that develop independent of each other. In TSC, attention deficits may occur as a consequence of earlier attention skills not developing correctly (de Vries & Watson).

When you are developing rules and routines, it is appropriate to involve the child as much as possible. Getting input in what the necessary consequence will be when the child does not follow through with a rule will get his/her buy-in. Be clear and specific about what you want the child to do. For example:

_I want you to clean your room on Saturdays._
You must remember that what you consider clean and what your child/adolescent considers clean may be two very different things.

*I want:*

- *Your floor picked up and vacuumed*
- *Your bed made*
- *Your furniture dusted*
- *All of your clothes hung up in your closet*

*By 4:00 pm on Saturdays.*

There is less room for misunderstanding what you mean when you are specific than when you just say “clean your room.” There should be a consequence written if they do not comply with your request, such as: *If your room is not cleaned by 4:00 pm on Saturday, you will not be allowed to go anywhere with your friends Saturday night.*

Remember there can not be any exceptions to the rule. The first time you make an exception it is downhill from there to get them to follow through with any of your requests.

Remember to post the rules in a visual place and read them many times throughout the week to remind and reinforce the rules with your child. This provides stability and structure to help individuals with ADHD build responsibility.

When you are giving direction, do not just ask them to do something.

For example:

*Wrong:* Will you please go to bed?

*Correct:* Go to bed it is your bedtime.

*Wrong:* Can you pick up after yourself?

*Correct:* Pick up your dishes and put them in the dishwasher.

*Wrong:* Won’t you please get up?

*Correct:* It is time to get up and get dressed.

If any of these issues are reoccurring, there should be rules defined and consequences for not doing them.
Example: Your bed time is 10:00 pm – that means in your bed and lights out. I will give you a warning at 9:30 p.m. and 9:45 p.m. If you are not in bed by 10:00 p.m., you will not be allowed to play your video games the next evening.

Example: Pick up your dirty dishes and put them in the dish washer. If you do not put your dishes in the dish washer after you use them, you will not be allowed to eat in the living room for two days.

Example: You are to get up and be ready for school by 7:30 a.m. I will call you at 6:30 a.m. and 6:45 a.m. to get you up. If you’re not out of bed and dressed by 7:30 a.m., you will not be allowed to have friends over that evening.

It is important to get input from your child as to what would be an appropriate consequence for the misbehavior. If the child plays a role in determining the consequence, they won’t be able to say that it is “unfair”. Remember: NEVER ARGUE because if you do, you lose every time. Just say “you know the rule” and just say it once. Then walk away and follow through with the consequence.

**Autistic Spectrum Disorder (ASD) and TSC**

Children with TSC may have high-functioning to severe ASD. Many of the individuals with high functioning ASD 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, as well as for individuals who are more severely affected. IDEA certainly stresses academic success, but it also encourages social and functional success as well. It takes everyone to make sure an individual with ASD develops the strategies needed to become independent and self-sufficient.

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 ASD may use behavior as a form of communication. In this situation, the behavior serves a purpose.

Some other possible reasons for the behavior can be:

- Caused by something in the environment
- To get attention
- To escape an unwanted activity
- Pain

People 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. According to Myles and Southwick (1999), three stages of overload are identified: (a) the rumbling stage, (b) the rage stage, and (c) the recovery stage. The authors state that the length of each stage may vary. One stage may last anywhere from an hour to a few minutes.

**The Rumbling Stage**

To show frustration or a general discomfort, individuals may:

- Bite the nails or lips
- Lower his or her voice
- Tense the muscles
- Tap the feet
- Grimace

These behaviors can serve as indicators of a person who with 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 child to develop appropriate ways to express frustration, 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. Parents and teachers can also use a variety of preventive strategies, developed by Myles and Southwick, to help ease the individual's anxiety or frustration such as:
• **Antiseptic bouncing** involves removing the individual, in a non-punitive fashion, from the environment in which he or she is experiencing difficulty. For example, you could ask a student to take a note to the teacher across the hall to give the opportunity for the student to regain a sense of calm before returning to the classroom.

• **Proximity control** is utilized when the parent or teacher moves near the individual who is engaged in the target behavior. The parent or teacher who circulates through a designated area is using proximity control.

• **Signal interference** is a nonverbal signal that informs the individual that the teacher or parent is aware of a seemingly minor precursor behavior. The teacher or parent can stand where eye contact can be made with the individual or a “secret” signal between teacher/parent and the individual can be used as a warning to watch the behavior.

• **Touch control** is another preemptive strategy that can be used to reduce challenging behavior. For example, the parent or teacher may gently touch the individual on the foot or leg to reduce tapping and stop disruptive behavior.

• **Support from routines** can be utilized as advanced preparation for a change in routine. Teachers or parents can display a chart or visual schedule of expectations and events that can provide security to the individual.

• **Interest boosting** involves showing a personal interest in an individual’s hobbies. This involves making the individual aware that you recognize his or her individual preferences.

• **Redirecting** involves helping the individual to focus on something other than the task at hand.

• **Home base** is another preemptive strategy parents or teachers can use to create a safe home base for individuals. This is a place where individuals can go when they feel a need to regain control.

• **Acknowledging individual difficulties** is a strategy parents and teachers can use to validate feelings and hopefully prevent the individual from getting stuck in the rumbling stage. For example, the teacher or parent should clearly state the rule along with the individual’s name, indicating that “everyone in the class/home follows the rule.”

• **Just walk and doesn’t talk** can be utilized with individuals who are not “runners.” The parent or teacher can walk with the individual and allow them to express their feelings without fear of discipline or logical argument. The adult should be calm, show as little reaction as possible, and never be confrontational.

**The Rage Stage**

Parents and teachers cannot always prevent challenging behavior. If the individual's behavior continues to escalate, an overload may occur. Myles and
Southwick refer to this as the rage stage. The individual may act impulsively, emotionally, or sometimes explosively. Individuals may bite, hit, kick, destroy property, or exhibit self-injurious behaviors. Once the rage stage is in effect, teachers or parents should let the overload run its course.

**The Recovery Stage**

Teachers and parents should then focus on helping the individual regain control. The third stage, *the recovery stage*, should be implemented when the individual is completely recovered. Parents and teachers should validate the individual’s feelings and teach self-awareness, self-monitoring, and coping strategies for future episodes.

**How Do I Get the School to Work with Me?**

Special education is a set of services and supports provided to children with disabilities to help them progress in the general education curriculum. The Individuals with Disabilities Education Act 2004 (IDEA 2004) is an education law designed to ensure children with disabilities are not only exposed to the general education curriculum but also progress in it through a free appropriate public education (FAPE).

When your child is diagnosed with tuberous sclerosis complex (TSC), the medical issues can be overwhelming and dealing with the school is the last thing you want to do. Many teachers and administrators are not familiar with disabilities in general, let alone in the area of TSC and behavior manifestations. Just because your child has TSC does not mean your child will automatically receive help in school. The law is very specific, and a child’s disability must adversely affect learning or he/she will not qualify to receive help in school. To further complicate matters, under the Individuals with Disabilities Education Act of 2004, the child must meet a certain criteria to even qualify. So, just because your child has a disability does not mean the school has to provide any kind of support or help.

A child with a disability is one who has been evaluated by the school system in accordance with the law and qualifies as a “child with a disability,” under IDEA 2004. Children are identified with a disability under the following categories:

- Mental Retardation (Intellectual Disability)
- Hearing Impairment
- Visual Impairment (including blindness)
- Serious Emotional Disturbance (referred to as Emotional Disturbance)
- Orthopedic Impairment
- Autism
• Traumatic Brain Injury
• Other Health Impairment
• Specific Learning Disability
• Deaf and/or Blindness
• Multiple Disabilities
• Speech or Language Impairments

To get special education services a child has to be identified as having a disability under one of these categories. The following procedures must be followed in identifying and evaluating a child with disability under IDEA 2004:

• Not discriminate based on race or culture
• Be given in the child’s native language or mode of communication unless it is clearly not feasible to do so
• Use a variety of tools and strategies
• Be validated for the purpose used
• Be given by a person who is trained/knowledgeable
• Be used in accordance with the test instructions
• Measure more than just IQ
• Accurately measure aptitude and/or achievement
• Use numerous tests in the evaluation process

If a child has more than one disability, he/she will qualify under the disability that most adversely affects learning, or he/she can be identified under multiple disabilities. If your child has intellectual disabilities and autism, he/she could be identified under either category depending on which is affecting learning the most. Is the developmental delay affecting his/her learning more than the autistic behaviors? If one does not outweigh the other, then you may want your child to be evaluated for multiple disabilities.

The school typically doesn’t know how a TSC diagnosis will impact learning, because TSC affects everyone differently. The school does not have to recognize the disability if officials feel it is not affecting your child’s learning. If your child is passing with Cs and Ds, the school will probably not want to test the child. You will then have to push to get them to understand, for example, that it might take your child two or three hours a night just to complete homework. Most school systems will only evaluate a child if he/she is failing.

Because school officials are not experts in TSC, they don’t always understand that your child is struggling and not just being lazy or not putting forth the greatest effort. Moreover, many times there are no outward signs of TSC. Since many regular educators don’t understand disabilities, they think that if they don’t see any visible signs of a disability, none must exist.
Getting the school to recognize that your child’s behavior is a manifestation of your child’s disability is important to receive appropriate services. You don’t want your child disciplined for a behavior that can’t be controlled. Having an appropriate behavior intervention plan will not only help, but will also protect your child from being targeted with inappropriate discipline procedures.

For example, if your child has ADHD, and disorganization and impulsivity are manifestations related to his disability, he or she may be reprimanded for not handing in homework, bringing materials to class, or for fidgeting and not paying attention. You want a positive behavior plan in place to teach the child strategies so they can remember to bring materials to class, pay attention, and hand in homework.

Problems may arise if you do not have an intervention plan in place to help your child be successful in school. If you are in this position, the first step is to write a letter requesting your child be evaluated for a disability under IDEA 2004. Put as much information in the request letter as possible describing the areas in which your child is struggling. Once you have requested the evaluation, the school will do one of three things:

1. Send you a “permission to evaluate form”
2. Refuse to evaluate until they do interventions
3. Refuse to evaluate

The school does not recognize your letter as a request to evaluate your child, even if that is what you stated in your letter. It will only recognize the school’s “permission to evaluate form.” Once you have signed that form, the school is required to evaluate your child within 60 calendar days (this is not school days) from the day you gave your consent to evaluate. School systems choose to only recognize their state-approved parent request form. So when writing your letter, make sure you give them a specific date by which they need to respond. To get the 60-day time frame going, you must sign their form stating you suspect your child of having a disability under IDEA 2004.

The school can also state it wants to do a Response to Intervention (RTI) model first. The school has authority to choose the RTI process to determine whether a child has a specific learning disability. They first determine if the child responds to scientific, research-based intervention. The problem with this type of intervention is that the 60-day time frame does not start until after the RTI process is completed. Sometimes it will be a full school year before the school will move forward with testing. That means your child may experience a year of failure and/or struggle before you can get them help. The idea of the RTI model is not a
bad practice if the school system is trained in the RTI process and the interventions used are in fact evidence-based research. These are the questions to ask:

1. How long are you planning on doing the RTI?
2. Am I involved in this process?
3. How are you going to collect data on the outcome of the RTI?
4. What is the evidence-based research to back the RTI you are using?

If the school system refuses to evaluate your child, you have no choice but to exercise your rights as a parent of a child with a disability. You want to proceed with the most un-adversarial approach, such as asking for a meeting with the person who runs the special education programs in your school district, who is sometimes called the Special Education Director. If you don’t know who this person is, go to your school district’s website and look for who is in charge of Special Education. If you do not have access to a computer, contact the TS Alliance at 1-800-225-6872 to ask for the Advocacy Department. We will assist you in finding the contact.

If this does not work, you will need to ask for a meeting with the superintendent. You would request a meeting with the superintendent and write a letter to the president of the school board. If the superintendent does not agree to have your child tested, you will proceed with a complaint to the State Department of Education. Most State Departments of Education have complaint forms on their websites. If you do not have access to a computer, contact the TS Alliance at 1-800-225-6872 and ask for the Advocacy Department to get help.

**Functional Behavior Assessment (FBA)**

When a child is in school and the behavior interferes with his/her learning and/or the learning of others, there should be a formal behavior intervention plan (BIP) placed on the students IEP or 504 Plan. Since behavior is a common issue for individuals with TSC, a functional behavior assessment (FBA) should be done to determine what triggers the behaviors. A FBA will give much-needed information to develop a positive behavior intervention plan (BIP).

To complete a FBA, there must be information gathered to determine what is causing the behavior. This information needs to be gathered through:

- Health and medical records
- Education evaluation testing
• Direct observations in the school environment (by more than one individual and in different settings)
• Observing in the home environment (parents, friends, relatives)

Once information has been gathered the questions to be answered are:

1. What behaviors do we want to modify or change?
2. Where does the behavior occur?
3. In what environment is the behavior occurring?
4. What is the common antecedent to the behavior?
5. Does there seem to be a pattern?
6. What is the trigger (reinforcer) for the behavior?
7. Why is the behavior occurring?
8. What more appropriate behavior can be taught to replace the inappropriate behavior?

This process cannot be done in an hour or be gathered by one person. There needs to be information gathered in structured and unstructured environments. Parents and medical health professionals should be part of the FBA process to know exactly what is causing the behaviors. When dealing with individuals with TSC, ruling out medical issues first will be of utmost importance. Medications, seizures, and other medical issues must be ruled out first. Sometimes, simple medication changes can have a major effect on behaviors.

**Behavior Intervention Plans**

Behavior intervention plans (BIP) must be in writing and placed on the student’s IEP. Just talking about putting a BIP in place does not make it happen. If there is a formal plan written and placed on a formal document, then the student is protected under the law. IDEA 2004 includes provisions in the law to protect a student with behaviors that are manifestations of the child’s disability.

A BIP should minimize the influences that cause the behavior. It should provide instruction in appropriate behavior to replace the problem behavior and identify accommodation and supports to promote the student’s success in social and academic areas. A BIP should be designed to teach social and problem-solving skills and should also address the student’s medical, physical or emotional needs.

Make sure the BIP:

• Is team-developed (including general educator input)
• Is based on the FBA
• Is in writing and incorporated into the IEP
• Modifies the antecedents before a behavior can occur
• Includes strategies to strengthen and teach appropriate behavior
• Includes modifications in curriculum or classroom expectations
• Provides a crisis intervention plan, if needed

When Behaviors Interfere with School Policy

Many times children with disabilities cannot follow school discipline policies because the behavior is a manifestation of the child’s disability. Many school systems have “zero tolerance” policies. Zero tolerance policies mean there will be no exception to the policy. If a behavior is a manifestation of the child’s disability, the school is punishing the child for having a disability.

Suspension and expulsion many times are the ways in which schools address consequences for behaviors. Children with disabilities are already struggling to keep up with their peers academically so suspending or expelling them is not appropriate. The law under IDEA 2004 has a discipline policy the school system must follow when dealing with behaviors and children with identified disabilities.

Understanding the Discipline Policy in IDEA 2004

The discipline part of IDEA 2004 can be complicated. When you have a child who is exhibiting problematic behaviors in school, you have to understand this part of the law. Many school districts have one answer to behavior: “suspension,” out of sight and out of mind. Unfortunately, this is not the answer for educating children when behavior is a manifestation of their disabilities. There are procedural safeguards for children with disabilities who have behavior manifestations.

10 School Days – The school district can suspend and/or expel a child with a disability up to 10 school days in one school year. This means a child with a disability is treated like any other child and will not receive any type of services during this time.

Remember that the 10 school days can be cumulative school days. Any time a child is taken out of the learning environment and is not being exposed to the general education curriculum counts toward these 10 days. If a child has spent half of a school day in the principal’s office for the last 20 school days, and is not receiving any instruction in the general education curriculum during his/her time in the office, the child has missed 10 days of instruction. The school will be required to provide the child with services on the next school day.
After the student has missed 10 school days, the school system has to provide free appropriate public education (FAPE). The school district determines what FAPE is and how the child will be served. The IEP team does not decide what services the child will receive unless it is a change in placement.

**Change in Placement** –

1. A change in placement should occur anytime a child is suspended or expelled for more than 10 consecutive school days. The school would have to suspend, expel, and not implement the IEP as written for 10 + 1 school days before this is considered a change in placement.
2. A change in placement occurs if the child has been subjected to a series of removals that constitute a pattern:
   - The series of removals total more than 10 school days in one year;
   - The child’s behavior is substantially similar to the child’s behavior in previous incidents that resulted in the series of removals; and/or
   - Additional factors such as the length of each removal, the total amount of time the child has been removed, and the proximity of the removals to one another.

**Manifestation Determination** – When a child with a disability has been suspended or expelled for more than 10 consecutive days, or subjected to a series of removals (change in placement), there has to be a manifestation determination. The parent and relevant members of the IEP team will meet to decide if the behavior is a manifestation of the child’s disability.

Within 10 school days of any decision to change the placement of a child with a disability because of a behavior, the parent and relevant members of the IEP team must review all pertinent information in the student’s file, including the child’s IEP, any teacher observations, and any information provided by the parents to determine:

- If the conduct in question was caused by or had a direct and substantial relationship to the child’s disability; and/or
- If the conduct in question was the direct result of the schools failure to implement the IEP.

*When the behavior is a manifestation of the disability:* The IEP team must conduct a *functional behavior assessment* (FBA) when the behavior is a manifestation of the disability. If there has been a FBA done and a behavior
intervention plan (BIP) put in place before the behavior has occurred and that behavior resulted in the change of placement, the team must review and modify the BIP to address the inappropriate behavior.

**When the behavior is not a manifestation of the disability:** The student will be suspended or expelled the same amount of time a child without a disability would be suspended or expelled.

The IEP team will decide FAPE for the child to continue to participate in the general education curriculum, *although in another setting*, and to progress toward meeting the goals set out in the child’s IEP. The child will also receive a FBA and BIP with services and modifications designed to address the behavior violation so it does not happen again.

**Unique circumstances**
The terms *unique circumstances* were added to the law in IDEA 2004. Basically it states that the school personnel may consider any unique circumstance on a case-by-case basis when determining whether to order a change in placement for a child with a disability who violates the code of student conduct.

**In the case of special circumstances related to drugs, weapons, or serious bodily injury**
A student who has possession of drugs or weapons, or who has caused serious bodily injury can be removed to an interim alternative setting by the school system for up to 45 school days without an IEP meeting. During the 45 school days, there must be a manifestation determination and a FBA and a BIP put into place.

**Notice required**
*On the date on which the decision* is made to make a removal that constitutes a change of placement, the school *must* notify the parents of that decision and provide parents with their rights. The parents have the right to send a letter to the school requesting an evaluation (see letter below).
Sample Letter

Date

Head of Special Education
Home School District
Address

To Mrs/Ms. XXXX:

I am the parent of (your child’s name) who attends school at (name of the school your child attends). I am requesting an evaluation under the Individuals with Disability Education Act 2004. I suspect my child of having a disability. (Describe the problems your child is having in education and why you feel your child needs special education services.)

Include:

- Diagnosis
- Recommendations of you physician
- Any additional information that explains TSC

Please consider this my permission to do the evaluation. If you have your own permission form, please forward it to me within the next five school days. If I do not hear from you I will consider this meets your requirements for my permission to do the evaluation.

Under IDEA 2004 it is my understanding that the evaluation will be completed within 60 days after you receive my permission to evaluate my child.

Sincerely,

Name cc: Principal
Address Superintendent
Phone:
e-mail
When There is a Change in Placement

Change in Placement

- Manifestation Determination
- Review FBA or do a FBA if one has not been done
- Determine if the behavior is a manifestation of the disability

The Behavior is a Manifestation of the Child’s Disability
- IEP Team Reviews the FBA and Develops BIP

The Behavior is NOT a Manifestation of the Child’s Disability
- Student Goes Back to School
- Student Does NOT go Back to School
- The IEP Team Decides FAPE
Resources

Positive Behavioral Interventions and Supports at www.pbis.org. Research based training for schools, funded/approved by U.S. Department of Education, which has chapters in most states and data to support the effectiveness of their programs.


IDEA requires a behavior plan be developed. This site for parents addresses how to do a behavior plan:
www.advocatesforspecialkids.org/pb_plan_samples_templates.htm.

Research findings on the effectiveness of involving families and students in school programs: www.hfrp.org.

Family/school partnerships are effective: “Building the Legacy” available on CD and online at National dissemination Center for Children with Disabilities (NICHCY):
www.nichcy.org/Laws/IDEA/Pages/BuildingTheLegacy.aspx.

No Child Left Behind, also on the NICHCY website with references to children with disabilities:

Supports for educators in learning about behavior strategies: Teacher-to-Teacher for a Federal Approach:

National Education Association (NEA): Offers information on working with students with disabilities at www.nea.org/home/16348.htm.

Council for Exceptional Children (CEC) page on support for teachers at:

Parent-to-Parent: Local support groups through schools and community perhaps, sibling support groups: www.siblingsupport.org.

Getting Information and Assistance: Office of Special Education Programs Technical Assistance and Dissemination (TA&D network), with great resources for schools and educators and also info for families includes all Parent Teacher Association Councils (PTAC): www.tadnet.org/home?format=html.

Other information and assistance is available from specific disability associations, including associations for low incidence disabilities. Information specific to each disabling condition, newsletters, conferences, on-line resources, support networks etc. at NICHCY: www.nichcy.org.

Supports for Teachers and Families: The Council for Children with Behavioral Disorders (CCBD), a division of the Council for Exceptional Children, is dedicated to supporting the professional development and enhancing the expertise of those who work on behalf of children with challenging behavior and their families: www.ccbd.net.

Supports for Families: Go to NICHCY’s Behavior Suite, which offers information on specific to behavior needs of children with disabilities: www.nichcy.org/pages/behaviorsuite.aspx.

An Introduction to TSC Associated Neuropsychiatric Disorders (TAND) and TAND Checklist, presented by Petrus J. de Vries, MBChB, MRCPsych, PhD. www.tsalliance.org/TAND
References

ATTENTION DEFICIT DISORDER: “Beyond the Myths," developed by the Chesapeake Institute, Washington, D.C.


2005 Burkhart Center for Autism Education & Research.


**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).

<table>
<thead>
<tr>
<th>STAGE</th>
<th>AGE RANGE</th>
<th>GENERAL PURPOSE OF ASSESSMENT</th>
<th>GENERAL AREAS TO ASSESS</th>
<th>AREAS OF PARTICULAR CONCERN IN TSC</th>
<th>BEHAVIORAL, PSYCHIATRIC, AND ACADEMIC DISORDERS OF PARTICULAR CONCERN IN TSC</th>
</tr>
</thead>
<tbody>
<tr>
<td>At diagnosis</td>
<td></td>
<td>Initial assessment of cognitive and behavioral profile</td>
<td>As listed for chronological age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infancy</td>
<td>Birth - 12 mos</td>
<td>To perform a baseline assessment for regular monitoring of development</td>
<td>Global standardized assessment of infant development</td>
<td>Impact of seizure onset and treatment on development</td>
<td></td>
</tr>
<tr>
<td>Toddler</td>
<td>1y - 2y11m</td>
<td>To identify early developmental disorders</td>
<td>Global intellectual ability and adaptive behaviors</td>
<td>Quality of eye contact, joint attention, reciprocity</td>
<td>Autism and autism spectrum disorders (ASD)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Specific skills:</td>
<td></td>
<td></td>
<td>Severe aggressive outbursts</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Gross and fine motor skills</td>
<td></td>
<td></td>
<td>Severe sleep problems</td>
</tr>
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<td></td>
<td></td>
<td>• Social-communication skills</td>
<td></td>
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</tr>
<tr>
<td>Pre-school</td>
<td>3 y to school entry</td>
<td>Evaluation of cognitive and behavioral profile to ensure the provision of appropriate educational programs</td>
<td>Global intellectual ability</td>
<td>Uneven profile of abilities</td>
<td>Autism and ASD</td>
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<tr>
<td></td>
<td></td>
<td>Specific neuropsychological skills:</td>
<td></td>
<td>Poor expressive language</td>
<td>ADHD and related disorders</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Receptive and expressive language</td>
<td></td>
<td>Poor reciprocity, peer interaction</td>
<td>Self-injurious behavior</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Social-communication skills</td>
<td></td>
<td>Poor regulation of affect and impulse</td>
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<td></td>
<td></td>
<td>• Attentional and executive skills</td>
<td></td>
<td>Poor bilateral coordination</td>
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<td></td>
<td></td>
<td>• Visuospatial skills</td>
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<td></td>
<td></td>
<td>• Motor skills</td>
<td></td>
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<tr>
<td>Early school years</td>
<td>6y-8y</td>
<td>Monitoring the child’s ability to make appropriate educational progress</td>
<td>Global intellectual abilities</td>
<td>Best time to establish baseline to assess whether specific cognitive skills and academic performance are discrepant from global intellectual abilities</td>
<td>Academic difficulties (reading, writing, spelling, mathematics)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Specific neuropsychological skills:</td>
<td></td>
<td>Poor expressive language and word retrieval</td>
<td>ADHD and related disorders</td>
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<tr>
<td></td>
<td></td>
<td>• Receptive and expressive language</td>
<td></td>
<td>Rote learning difficulties</td>
<td>Peer problems</td>
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<tr>
<td></td>
<td></td>
<td>• Social-communication skills</td>
<td></td>
<td>Selective attention, sustained attention difficulties</td>
<td>Aggressive behaviors</td>
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<td></td>
<td></td>
<td>• Attentional and executive skills</td>
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<td>• Visuospatial skills</td>
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<td>• Motor skills</td>
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The consensus clinical guidelines for the assessment of TAND (continued)

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Middle school years</td>
<td>9y-12y</td>
<td>Comprehensive review of child’s abilities, specific learning difficulties, and behavioral problems in preparation for transition to secondary education</td>
<td>Global intellectual abilities</td>
<td>Subtle deficits of social communication, unusual interests</td>
<td>High functioning ASD/Asperger’s</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Specific neuropsychological skills:</td>
<td>Poor working memory, episodic memory</td>
<td>Peer problems</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Receptive and expressive language</td>
<td>Planning, organizational abilities, multitasking difficulties</td>
<td>Academic difficulties (reading, writing, spelling, mathematics)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Social-communication skills</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>• Memory skills                                                                _LINUX</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Attentional and executive skills</td>
<td></td>
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<tr>
<td>Adolescence</td>
<td>13y-16y</td>
<td>Determining individual needs and the support required for transition into adulthood</td>
<td>Global intellectual abilities</td>
<td>Poor judgement, decision-making</td>
<td>Depressive disorders</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Specific neuropsychological skills:</td>
<td></td>
<td>Anxiety disorders</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Attentional and executive skills</td>
<td></td>
<td>Peer problems</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Vocational assessment with knowledge of cognitive strengths and weaknesses</td>
<td></td>
<td>Epilepsy-related psychotic disorders</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Adaptive behavior and daily living skills</td>
<td></td>
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<tr>
<td>Adults</td>
<td>18y+</td>
<td>Newly diagnosed adults: Assessment of cognitive, behavioral and vocational profile, determining bio-psycho-social needs</td>
<td>Global intellectual abilities</td>
<td>Difficulty with integrational skills</td>
<td>Depressive disorders</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Specific neuropsychological skills:</td>
<td>Working memory, episodic memory problems</td>
<td>Anxiety disorders</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Attentional and executive skills</td>
<td></td>
<td>Epilepsy-related psychotic disorders</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Memory skills                                                                _LINUX</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults (follow-up)</td>
<td>18y+</td>
<td>Monitoring for emergence of psychiatric problems or changes in existing cognitive and behavioral profile</td>
<td>Dependent adults: Annual review of social care needs and support</td>
<td>Pay particular attention to change in cognitive abilities or behavior</td>
<td>Depressive disorders</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Independent adults:                                                                _LINUX</td>
<td>Pay particular attention to change in cognitive abilities, vocational performance and behavior</td>
<td>Anxiety disorders</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Vocational advice                                                                _LINUX</td>
<td></td>
<td>Epilepsy-related psychotic disorders</td>
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<td></td>
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<td></td>
<td>• Genetic counseling as appropriate</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>• Review if problems arise                                                                _LINUX</td>
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</tbody>
</table>

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.
Tuberous Sclerosis Complex (TSC) is associated with a range of neuropsychiatric disorders which we refer to as TAND (TSC–Associated–Neuropsychiatric–Disorders). All people with TSC are at risk of having some of these difficulties. Some people with TSC have very few, while others will have many of them. Each person with TSC will therefore have their own TAND profile, and this profile may change over time. This checklist was developed to help clinical teams, individuals with TSC and their families a) screen for TAND at every clinic visit and b) prioritize what to do next.

Instructions for use
The TAND Checklist was designed to be completed by a clinician with relevant knowledge and experience in TSC, in partnership with individuals with TSC or their parents/carers. The Checklist should take about 10 minutes to complete. Where individuals answer YES to an item, the clinician should explore the difficulty in sufficient detail to help guide decisions about further evaluation or treatment. All items should be completed.

About the interview
Name of TSC Subject: ...........................................
Name of Interviewer: ...........................................
Name of interviewee: ...........................................
DOB: d d m m y y Age: 
Date of interview: d d m m y y 
Self / Parent / Carer / Other (circle)

Let’s begin
As you will know, the majority of people with TSC have some difficulty in learning, behaviour, mental health, specific aspects of their development and so on. We are going to use this checklist to help us check for these kinds of difficulties. I am going to ask you a number of questions. Some may be directly relevant; some might not be relevant at all. Just answer as best as you can. At the end I will check to see if there are any additional difficulties we didn’t talk about.

For parents/carers of individuals with TSC, please start with question 1.
For individuals with TSC who complete this about themselves, please start with question 3.

01 Let’s begin by talking about [subject]’s development to get a sense of where they are at. How old was [subject] when he/she:

a. First smiled?  
Age: Not yet:  
b. Sat without support?  
Age: Not yet:  
c. Walked without holding on?  
Age: Not yet:  
d. Used single words other than “mama” or “dada”?  
Age: Not yet:  
e. Used two words/short phrases?  
Age: Not yet:  
f. Was toilet trained during the day?  
Age: Not yet:  
g. Was toilet trained at night?  
Age: Not yet:
What is [subject]’s current level of *(please tick)*:

- **a. Language:**
  - [ ] non-verbal
  - [ ] simple language
  - [ ] fluent

- **b. Self-care:**
  - [ ] dependent on others
  - [ ] some self-care skills
  - [ ] independent

- **c. Mobility:**
  - [ ] wheelchair
  - [ ] needs significant support
  - [ ] some difficulty
  - [ ] completely mobile

Let’s talk about behaviours causing concern to you or to other people. Have/has [subject] ever had difficulty with any of the following?

- **a. Anxiety**
  - [ ] NO
  - [ ] YES

- **b. Depressed mood**
  - [ ] NO
  - [ ] YES

- **c. Extreme shyness**
  - [ ] NO
  - [ ] YES

- **d. Mood swings**
  - [ ] NO
  - [ ] YES

- **e. Aggressive outbursts**
  - [ ] NO
  - [ ] YES

- **f. Temper Tantrums**
  - [ ] NO
  - [ ] YES

- **g. Self-injury, such as hitting self, biting self, scratching self**
  - [ ] NO
  - [ ] YES

- **h. Absent or delayed onset of language to communicate**
  - [ ] NO
  - [ ] YES

- **i. Repeating words or phrases over and over again**
  - [ ] NO
  - [ ] YES

- **j. Poor eye contact**
  - [ ] NO
  - [ ] YES

- **k. Difficulties getting on with other people of similar age**
  - [ ] NO
  - [ ] YES

- **l. Repetitive behaviours, *such as doing the same thing over and over again***
  - [ ] NO
  - [ ] YES

- **m. Very rigid or inflexible about how to do things or not liking change in routines**
  - [ ] NO
  - [ ] YES

- **n. Overactivity/hyperactivity, *such as being constantly on the go***
  - [ ] NO
  - [ ] YES

- **o. Difficulty paying attention or concentrating**
  - [ ] NO
  - [ ] YES

- **p. Restlessness or fidgetiness, *such as wriggling or squirming***
  - [ ] NO
  - [ ] YES

- **q. Impulsivity, *such as butting in, not waiting turn***
  - [ ] NO
  - [ ] YES

- **r. Difficulties with eating, *such as eating too much, too little, unusual things***
  - [ ] NO
  - [ ] YES

- **s. Sleep difficulties, *such as with falling asleep or waking***
  - [ ] NO
  - [ ] YES

If you answered YES to any of the above:

- **Have you had further evaluation or support for it?**
  - [ ] NO
  - [ ] YES

- **Would you like to have further evaluation or support for it?**
  - [ ] NO
  - [ ] YES

Problem behaviours may add up to meet criteria for specific psychiatric disorders. Have/has [subject] ever received a diagnosis of:

- **a. Autism Spectrum Disorder (ASD), including autism, Asperger’s**
  - [ ] NO
  - [ ] YES

- **b. Attention Deficit Hyperactivity Disorder (ADHD)**
  - [ ] NO
  - [ ] YES

- **c. Anxiety Disorder, *including as panic, phobia, separation anxiety disorder***
  - [ ] NO
  - [ ] YES

- **d. Depressive Disorder**
  - [ ] NO
  - [ ] YES

- **e. Obsessive Compulsive Disorder**
  - [ ] NO
  - [ ] YES

- **f. Psychotic Disorder, *including schizophrenia***
  - [ ] NO
  - [ ] YES

If you answered YES to any of the above:

- **Have you had further evaluation or support for it?**
  - [ ] NO
  - [ ] YES

- **Would you like to have further evaluation or support for it?**
  - [ ] NO
  - [ ] YES
05 About half of people with TSC will have significant difficulties in their overall intellectual development and may have ‘intellectual disability’.

a. Have you ever been concerned about this for [subject]?
   NO ☐ YES ☐

b. Have/has [subject] ever had a formal evaluation of intelligence by a professional using IQ-type tests?
   NO ☐ YES ☐

   If YES, what did results show?
   - Normal Intellectual Ability (IQ > 80)
   - Borderline Intellectual Ability (IQ 70-80)
   - Mild Intellectual Disability (IQ 50-69)
   - Moderate Intellectual Disability (IQ 35-49)
   - Severe Intellectual Disability (IQ 21-34)
   - Profound Intellectual Disability (IQ <20)

   c. What is your view of [subject]’s intellectual ability?
   - Normal Intellectual Ability ☐
   - Mild-Moderate Intellectual Disability ☐
   - Severe - Profound Intellectual Disability ☐

   d. Would you like to have further evaluation or support for it?
   NO ☐ YES ☐

06 Many people with TSC who are of school age will have difficulty in school.

[For individuals of school age]: Does/do [subject] have any difficulty with any of the following:

a. Reading
   N/A ☐ NO ☐ YES ☐

b. Writing
   N/A ☐ NO ☐ YES ☐

c. Spelling
   N/A ☐ NO ☐ YES ☐

d. Mathematics
   N/A ☐ NO ☐ YES ☐

If you answered YES to any of the above

Have/has [subject] had further evaluation or support for it?
   NO ☐ YES ☐

Have/has [subject] been considered for any additional support in school such as extra help or an Individual Educational Plan (IEP)?
   NO ☐ YES ☐

Would you like to have further evaluation or support for [subject]?
   NO ☐ YES ☐

07 The majority of people with TSC will have some difficulties in some specific brain skills. Do/does [subject] have difficulty with any of the following:

a. Memory, such as remembering things that have happened
   NO ☐ YES ☐

b. Attention, such as concentrating well, not getting distracted
   NO ☐ YES ☐

c. Dual-tasking/ Multi-tasking, such as doing 2 tasks at the same time
   NO ☐ YES ☐

d. Visuo-spatial tasks, such as solving puzzles or using building blocks
   NO ☐ YES ☐

e. Executive skills, such as planning, organizing, flexible thinking
   NO ☐ YES ☐

f. Getting disoriented, such as not knowing the date or where you are
   NO ☐ YES ☐

If you answered YES to any of the above

Have/has [subject] had further evaluation or support for it?
   NO ☐ YES ☐

Would you like to have further evaluation or support for these difficulties?
   NO ☐ YES ☐
Apart from the challenges listed above, TSC can have a big impact on people’s lives in other ways. Have/has [subject] had any difficulties with:

a. Low self-esteem  NO  YES
b. Very high levels of stress in families, for instance between siblings  NO  YES
c. Very high levels of stress between parents leading to significant relationship difficulties  NO  YES

If you answered YES to any of the above

Have/has [subject] and/or your family had further evaluation or support for it?  NO  YES

Would you like to have further evaluation or support for it?  NO  YES

Taking together all the difficulties discussed above, how much have these bothered, troubled or distressed you/your child/family?

Not at all  0  1  2  3  4  5  6  7  8  9  10  Extremely

Of all the concerns listed above, what are your top priorities to work on next?

a. .............................................................................................................................................................................................................

b. .............................................................................................................................................................................................................

c. .............................................................................................................................................................................................................

Do you have any other worries about TAND for [subject] that we have not talked about as we went through the checklist?

NO  YES  If YES, please list: .............................................................................................................................................................................................................

.............................................................................................................................................................................................................

.............................................................................................................................................................................................................

.............................................................................................................................................................................................................

.............................................................................................................................................................................................................

Thank You!

Interviewer’s judgement of impact/burden on the individual/child/family.

Not at all  0  1  2  3  4  5  6  7  8  9  10  Extremely