

THE TAND CHECKLIST

Lifetime version (TAND-L)

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: DOB: / / Age:

Name of Interviewer: Date of interview: / /

Name of interviewee: Self / Parent / Carer / Other (circle)

Let's begin

As you will know, the majority of people with TSC have some difficulty in learning, behavior, 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: <input type="text"/> | Not yet: <input type="checkbox"/> |
| b. Sat without support? | Age: <input type="text"/> | Not yet: <input type="checkbox"/> |
| c. Walked without holding on? | Age: <input type="text"/> | Not yet: <input type="checkbox"/> |
| d. Used single words other than "mama" or "dada"? | Age: <input type="text"/> | Not yet: <input type="checkbox"/> |
| e. Used two words/short phrases? | Age: <input type="text"/> | Not yet: <input type="checkbox"/> |
| f. Was toilet trained during the day? | Age: <input type="text"/> | Not yet: <input type="checkbox"/> |
| g. Was toilet trained at night? | Age: <input type="text"/> | Not yet: <input type="checkbox"/> |

02

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

03

Let's talk about behaviors 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 behaviors, 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

04

Problem behaviors 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 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:

[For individuals after school age]: Did [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

08

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

09

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

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

- a.
- b.
- c.

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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:.....

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Thank You!

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Interviewer's judgment of impact/burden on the individual/child/family.

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