English version

TAND-SQ

Self-report, Quantified TAND Checklist (2023)

Tuberous Sclerosis Complex (TSC) is associated with a range of neuropsychiatric disorders that we refer to as **TAND** (**T**SC–**A**ssociated **N**europsychiatric **D**isorders). 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 these difficulties. Each person with TSC will therefore have their own TAND profile, and this profile may change over time. This checklist was developed for individuals and families who live with TSC to complete for themselves with the goal of a) screening for TAND difficulties at home, b) to quantify these difficulties, and c) to help guide next steps for self-help and for further discussions with healthcare and other service providers.

Let's get started

Name of the person completing the TAND-SQ Checklist:

.....

Date you completed the TAND-SQ Checklist: d d / m m / y y y y

Who is the TAND-SQ Checklist about? This checklist will refer to this person as [subject].

☐ Myself ☐ My son ☐ My daughter ☐ My partner ☐ My mother ☐ My father
☐ My brother ☐ My sister ☐ My grandchild ☐ Other (please specify).....

Name of the person [subject]: .....

Date of birth: d d / m m / y y y y **Age:** ☐ **Sex:** ☐ Male ☐ Female ☐ Other

Preferred personal pronouns: ☐ He/Him/His ☐ She/Her/Hers ☐ They/Them/Theirs

Instructions for use

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. The TAND-SQ Checklist was designed to help parents/caregivers or individuals with TSC to check for these kinds of difficulties. The checklist should take about 20 – 30 minutes to complete. You will see a number of questions. Some may be directly relevant and some might not be relevant at all. Some of the items can be quantified (given a severity rating) based on how good or difficult things have been *over the last month*. Even if you can't remember everything, just answer as best as you can and please try to complete all items. At the end we will show you how to identify your own TAND Cluster Profile that may help you plan your next steps.

Where you see the pencil sign we have created space for you to make short notes if that would be helpful to you.

If you are caring for someone with TSC, please start with question 1.

If you have TSC and you are completing the TAND-SQ for yourself, 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 they:

a. First smiled?

☐ Not yet ☐ < 2 months ☐ 2 – 4 months ☐ 4 – 6 months ☐ > 6 months
☐ Not sure *(within normal range)* ☐ Not sure *(delayed)*

b. Sat without support?

☐ Not yet ☐ < 6 months ☐ 6 – 8 months ☐ 8 – 10 months ☐ 10 – 12 months
☐ > 12 months ☐ Not sure *(within normal range)* ☐ Not sure *(delayed)*

c. Walked without holding on?

☐ Not yet ☐ < 10 months ☐ 10 – 12 months ☐ 12 – 14 months ☐ 14 – 16 months
☐ 16 – 18 months ☐ > 18 months ☐ Not sure *(within normal range)* ☐ Not sure *(delayed)*

d. Used single words other than 'mama' or 'dada'?

☐ Not yet ☐ < 12 months ☐ 12 – 14 months ☐ 14 – 16 months ☐ 16 – 18 months
☐ 18 – 20 months ☐ > 20 months ☐ Not sure *(within normal range)* ☐ Not sure *(delayed)*

e. Used two word or simple phrases (e.g. play park, drink juice...)?

☐ Not yet ☐ < 18 months ☐ 18 – 22 months ☐ 22 – 26 months ☐ 26 – 30 months
☐ 30 – 36 months ☐ > 36 months ☐ Not sure *(within normal range)* ☐ Not sure *(delayed)*

f. Was toilet trained during the day?

☐ Not yet ☐ < 24 months ☐ 24 – 30 months ☐ 30 – 36 months ☐ 36 – 48 months
☐ > 48 months ☐ Not sure *(within normal range)* ☐ Not sure *(delayed)*

g. Was toilet trained at night?

☐ Not yet ☐ < 3 years ☐ 3 – 4 years ☐ 4 – 5 years ☐ 5 – 6 years
☐ 6 – 8 years ☐ > 8 years ☐ Not sure *(within normal range)* ☐ Not sure *(delayed)*

.....

.....

02

What is [subject]'s current level of:

a. Language: ☐ non-verbal/minimally 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 behaviours causing concern to you or to other people.

a. Has **anxiety** ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

b. Has **depressed mood** ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

c. Has **extreme shyness** ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

d. Have **mood swings** ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

e. Have **aggressive outbursts** ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

f. Have **temper tantrums** ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

g. Has **self-injury**, *such as hitting self, biting self, scratching self*, ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

h. Has **absence or delayed onset of language** ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

i. Has **repeating words or phrases over and over again** ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

j. Has **poor eye contact** ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

k. Has **getting on with other people of a similar age** ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

l. Have **repetitive behaviours**, *such as doing the same thing over and over again*, ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

m. Has **very rigid or inflexible behaviour**, *such as wanting to do things in a particular way or not liking change in routines*, ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

n. Have **sensory sensitivities (hyper- or hyposensitivity)**, *such as either being very interested in or very sensitive to the sight, smell, touch or sound of things*, ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

o. Has **overactivity/hyperactivity**, *such as being constantly on the go*, ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

p. Has **paying attention or concentrating** ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

q. Has **restlessness or fidgetiness**, *such as wriggling or squirming*, ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

r. Has **impulsivity**, *such as butting in or not waiting your turn*, ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

s. Has **eating and/or drinking**, *such as too much, too little, unusual things*, ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

t. Has **sleep**, *such as falling asleep or waking*, ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

u. Have **any other behaviours** ever been a problem? NO ☐ YES ☐

If YES, please list and specify how much of a problem it has been *over the last month?* Score (0-10)

1. ..... ☐

2. ..... ☐

3. ..... ☐

If you answered YES to any of the items in question 3:

– Have you/has [subject] had further evaluation or support for any of these behavioural difficulties? NO ☐ YES ☐

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

.....

.....

04 Problem behaviours may add up to meet criteria for specific psychiatric disorders. Have you/has [subject] ever received a diagnosis using standardised assessments/ tools of any of the following:

a. Autism Spectrum Disorder (ASD), *including autism, Asperger's* NO ☐ YES ☐

b. Attention Deficit Hyperactivity Disorder (ADHD) NO ☐ YES ☐

c. Anxiety Disorder, *including panic, phobia, separation anxiety disorder* NO ☐ YES ☐

d. Depressive Disorder NO ☐ YES ☐

e. Obsessive Compulsive Disorder (OCD) NO ☐ YES ☐

f. Psychotic Disorder, *including schizophrenia* NO ☐ YES ☐

g. Other psychiatric disorder(s)? NO ☐ YES ☐

If YES, please specify here.

1. .....
2. .....
3. .....

If you answered YES to any of the items in question 4:

– Have you/has [subject] had further evaluation or support for any of these psychiatric disorders? NO ☐ YES ☐

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

b. Have you/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) ☐
- I don't know ☐

c. What is your view of your/[subject]'s intellectual ability?

- Above Average Intellectual Ability ☐
- Normal Intellectual Ability ☐
- Mild – Moderate Intellectual Disability ☐
- Severe – Profound Intellectual Disability ☐

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

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

a. Has **reading** ever been a problem? Not yet in school ☐ NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

b. Has **writing** ever been a problem? Not yet in school ☐ NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

c. Has **spelling** ever been a problem? Not yet in school ☐ NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

d. Has **mathematics** ever been a problem? Not yet in school ☐ NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

e. Have there ever been **any other difficulties** related to learning in school?

Not yet in school ☐ NO ☐ YES ☐

If YES, please list and specify how much of a problem it has been *over the last month?* Score (0-10)

1. ..... ☐
2. ..... ☐
3. ..... ☐

If you answered YES to any of the items in question 6:

– Have you/has [subject] had further evaluation or support for any of these scholastic difficulties?
NO ☐ YES ☐

– Have you/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 yourself/[subject]? NO ☐ YES ☐

.....

.....

07 The majority of people with TSC will have difficulties in some specific brain skills.

a. Have **motor skills**, *such as clumsiness, poor coordination or gait problems*, ever been a problem?

NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

b. Have **language skills**, *such as difficulty understanding or expressing language*, ever been a problem?

NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

c. Has **attention**, *such as concentrating well, not getting distracted*, ever been a problem?

NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

d. Has **dual-tasking/multi-tasking**, *such as doing two tasks at the same time*, ever been a problem?

NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

e. Has **memory**, *such as remembering things that have happened*, ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

f. Have **visuo-spatial tasks**, *such as solving puzzles or using building blocks,* ever been a problem?

NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

g. Have **executive skills**, *such as planning, organising or flexible thinking*, ever been a problem?

NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

h. Has **being disoriented**, *such as not knowing the date or where you are*, ever been a problem?

NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

i. Has **processing speed**, *such as being very slow to do a task*, ever been a problem? NO ☐ YES ☐

If YES, how much of a problem has it been *over the last month?*

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

.....

.....

j. Have **any other brain skills** ever been a problem? NO ☐ YES ☐

If YES, please list and specify how much of a problem it has been *over the last month?* Score (0-10)

1. ..... ☐

2. ..... ☐

3. ..... ☐

If you answered YES to any of the items in question 7:

– Have you/has [subject] had further evaluation or support for any of these neuropsychological difficulties? NO ☐ YES ☐

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

.....

.....

08

Apart from the challenges listed above, TSC can have a big impact on people's lives in other ways.

– If you have TSC, please complete question 8.1.

– If you are a caregiver, please complete question 8.1 for [subject] *and* question 8.2 for yourself as caregiver.

8.1

Have you/has [subject] ever had any difficulties with:

a. Low self-esteem NO ☐ YES ☐

b. Very high levels of stress *in the family* NO ☐ YES ☐

c. Very high levels of stress *in relationship with siblings* NO ☐ YES ☐

d. Very high levels of *parent-child relationship difficulties* NO ☐ YES ☐

e. Very high levels of *parent-to-parent/partner relationship difficulties* NO ☐ YES ☐

f. Very high levels of stress leading to *difficulty for the family to connect with others in their community* NO ☐ YES ☐

g. Very high levels of stress leading to *difficulty for you to progress in your career* NO ☐ YES ☐

If you answered YES to any of the items in question 8.1:

– Have you and/or your family had further evaluation or support for any of these psychosocial difficulties? NO ☐ YES ☐

– Would you like to have further evaluation or support for it for you and/or your family? NO ☐ YES ☐

.....

.....

8.2

As the caregiver, have you ever had difficulties with:

a. Low self-esteem NO ☐ YES ☐

b. Very high levels of stress *in your family* NO ☐ YES ☐

c. Very high levels of stress *in your relationship with your siblings* NO ☐ YES ☐

d. Very high levels of *parent-child relationship difficulties* NO ☐ YES ☐

e. Very high levels of *parent-to-parent/partner relationship difficulties* NO ☐ YES ☐

f. Very high levels of stress leading to *difficulty for your family to connect with others in your community* NO ☐ YES ☐

g. Very high levels of stress leading to *difficulty for you to progress in your career* NO ☐ YES ☐

If you answered YES to any of the items in question 8.2:

– Have you and/or your family had further evaluation or support for any of these psychosocial difficulties? NO ☐ YES ☐

– Would you like to have further evaluation or support for it for you and/or your family? NO ☐ YES ☐

.....

.....

09 Please feel free to make notes of any other worries about TAND that were not covered in the TAND-SQ Checklist.

10 Taking together all the difficulties discussed in the TAND-SQ Checklist, how much have these bothered, troubled or distressed you and/or your family *over the last month?*

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

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

12 We all develop or learn strategies to manage our day-to-day lives with TAND. Write down any strategies that are helping you/[subject] at the moment. This could be helpful when monitoring progress over time.

13 So far we have focused on difficulties and challenges. However, our journeys with TSC often also bring good things. Each person with TSC has their own strengths, skills and talents that can bring joy into our lives! Write down some of those good things, thinking particularly *over the last month*. This may include happy moments, small victories, or anything else you might be celebrating at the moment.

14 TAND Cluster Profile

Now that you have rated the TAND challenges you/[subject] may be experiencing, here we will help you identify your own TAND Cluster Profile. We hope that this will help you to plan your next steps for assessment, intervention and support.

The seven natural TAND Clusters*

This table shows all the items that make up specific TAND Clusters. If you ticked 'YES' for any of these items in **question 3** (p3), **question 6** (p8) or **question 7** (p9) of the TAND-SQ Checklist, make a tick in the relevant row. Once you have gone through the whole list, you will see which of the seven natural TAND Clusters might be relevant to you and your family.

TAND-SQ Checklist Number and Checklist Item	Autism-like cluster	Dysregulated behaviour cluster	Eat/sleep cluster	Mood/anxiety cluster	Neuropsycho-logical cluster	Overactive/ Impulsive cluster	Scholastic cluster
3a Anxiety	–	–	–	☐	–	–	–
3b Depressed mood	–	–	–	☐	–	–	–
3c Extreme shyness	–	–	–	☐	–	–	–
3d Mood swings	–	–	–	☐	–	–	–
3e Aggressive outbursts	–	☐	–	–	–	–	–
3f Temper tantrums	–	☐	–	–	–	–	–
3g Self-injury	–	☐	–	–	–	–	–
3h Delayed language	☐	–	–	–	–	–	–
3i Repeating words / phrases	☐	–	–	–	–	–	–
3j Poor eye contact	☐	–	–	–	–	–	–
3k Getting on with peers	☐	–	–	–	–	–	–
3l Repetitive behaviour	☐	–	–	–	–	–	–
3m Rigid or inflexible behaviour	☐	–	–	–	–	–	–
3o Overactivity	–	–	–	–	–	☐	–
3p Paying attention / concentrating	–	–	–	–	☐	–	–
3q Restlessness / fidgetiness	–	–	–	–	–	☐	–
3r Impulsivity	–	–	–	–	–	☐	–
3s Eating difficulties	–	–	☐	–	–	–	–
3t Sleeping difficulties	–	–	☐	–	–	–	–
6a Reading difficulties	–	–	–	–	–	–	☐
6b Writing difficulties	–	–	–	–	–	–	☐
6c Spelling difficulties	–	–	–	–	–	–	☐
6d Mathematics difficulties	–	–	–	–	–	–	☐
7c Neuropsychological attention deficits	–	–	–	–	☐		
7d Dual-tasking / multi-tasking difficulties	–	–	–	–	☐	–	–
7e Memory difficulties	–	–	–	–	☐	–	–
7f Visuo-spatial difficulties	–	–	–	–	☐	–	–
7g Executive difficulties	–	–	–	–	☐	–	–
7h Disorientation	–	–	–	–	☐	–	–

The Wraparound Psychosocial Cluster

If you ticked 'YES' for any of the items in **question 8** (p11) of the TAND-SQ Checklist, make a tick in the relevant row below. It will show whether the psychosocial cluster might be an area of concern to you.

		Psychosocial Cluster – Individual	Psychosocial Cluster – Caregiver
8.1a	Low self-esteem	☐	
8.1b	Stress in family	☐	
8.1c	Stress in sibling relationships	☐	
8.1d	Parent-child relationship difficulties	☐	
8.1e	Parent-parent/partner relationship difficulties	☐	
8.1f	Difficulty connecting in community	☐	
8.1g	Difficulties in career	☐	
8.2a	Low self-esteem		☐
8.2b	Stress in family		☐
8.2c	Stress in sibling relationships		☐
8.2d	Parent-child relationship difficulties		☐
8.2e	Parent-parent/partner relationship difficulties		☐
8.2f	Difficulty connecting in community		☐
8.2g	Difficulties in career		☐

*This table is based on the natural TAND clusters as identified in a paper published by de Vries and colleagues in *Orphanet Journal of Rare Diseases*, 2021, 16: 447. You may notice that the TAND-SQ has additional items not included in the earlier cluster work.

.....

.....

Thank You!

The TAND-SQ Checklist is distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International Licence (http://creativecommons.org/). The TAND-SQ Checklist may be copied, reproduced and used in paper format for non-commercial purposes provided that the original work is properly credited and that no changes are made to the checklist. For any enquiries regarding use of the TAND-SQ Checklist, please contact Prof. Petrus de Vries (petrus.devries@uct.ac.za).