

# 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 (**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 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:

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Date you completed the TAND-SQ Checklist:   /   /

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:   /   /     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*)



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# 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



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# 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



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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



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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



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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



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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



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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



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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



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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



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**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



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**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



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**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



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**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



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**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



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**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



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**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



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**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



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# 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



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# 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



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**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



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**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



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**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



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**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



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# 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



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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



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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



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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



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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



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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



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**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



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**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



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**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



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**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



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# 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 <input type="checkbox"/> | YES <input type="checkbox"/> |
| b. Very high levels of stress <i>in the family</i>  | NO <input type="checkbox"/> | YES <input type="checkbox"/> |
| c. Very high levels of stress <i>in relationship with siblings</i>  | NO <input type="checkbox"/> | YES <input type="checkbox"/> |
| d. Very high levels of <i>parent-child relationship difficulties</i>  | NO <input type="checkbox"/> | YES <input type="checkbox"/> |
| e. Very high levels of <i>parent-to-parent/partner relationship difficulties</i>                                    | NO <input type="checkbox"/> | YES <input type="checkbox"/> |
| f. Very high levels of stress leading to <i>difficulty for the family to connect with others in their community</i> | NO <input type="checkbox"/> | YES <input type="checkbox"/> |
| g. Very high levels of stress leading to <i>difficulty for you to progress in your career</i>                       | NO <input type="checkbox"/> | YES <input type="checkbox"/> |

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



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## 8.2

As the caregiver, have you ever had difficulties with:

- |   |                             |                              |
|---|-----------------------------|------------------------------|
| a. Low self-esteem  | NO <input type="checkbox"/> | YES <input type="checkbox"/> |
| b. Very high levels of stress <i>in your family</i>   | NO <input type="checkbox"/> | YES <input type="checkbox"/> |
| c. Very high levels of stress <i>in your relationship with your siblings</i>  | NO <input type="checkbox"/> | YES <input type="checkbox"/> |
| d. Very high levels of <i>parent-child relationship difficulties</i>  | NO <input type="checkbox"/> | YES <input type="checkbox"/> |
| e. Very high levels of <i>parent-to-parent/partner relationship difficulties</i>                                    | NO <input type="checkbox"/> | YES <input type="checkbox"/> |
| f. Very high levels of stress leading to <i>difficulty for your family to connect with others in your community</i> | NO <input type="checkbox"/> | YES <input type="checkbox"/> |
| g. Very high levels of stress leading to <i>difficulty for you to progress in your career</i>                       | NO <input type="checkbox"/> | YES <input type="checkbox"/> |

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



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



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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?



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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.



Four horizontal dotted lines for writing notes.

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.



Four horizontal dotted lines for writing notes.

# 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	Neuropsychological cluster	Overactive/Impulsive cluster	Scholastic cluster
3a Anxiety	-	-	-	<input type="checkbox"/>	-	-	-
3b Depressed mood	-	-	-	<input type="checkbox"/>	-	-	-
3c Extreme shyness	-	-	-	<input type="checkbox"/>	-	-	-
3d Mood swings	-	-	-	<input type="checkbox"/>	-	-	-
3e Aggressive outbursts	-	<input type="checkbox"/>	-	-	-	-	-
3f Temper tantrums	-	<input type="checkbox"/>	-	-	-	-	-
3g Self-injury	-	<input type="checkbox"/>	-	-	-	-	-
3h Delayed language	<input type="checkbox"/>	-	-	-	-	-	-
3i Repeating words / phrases	<input type="checkbox"/>	-	-	-	-	-	-
3j Poor eye contact	<input type="checkbox"/>	-	-	-	-	-	-
3k Getting on with peers	<input type="checkbox"/>	-	-	-	-	-	-
3l Repetitive behaviour	<input type="checkbox"/>	-	-	-	-	-	-
3m Rigid or inflexible behaviour	<input type="checkbox"/>	-	-	-	-	-	-
3o Overactivity	-	-	-	-	-	<input type="checkbox"/>	-
3p Paying attention / concentrating	-	-	-	-	<input type="checkbox"/>	<input type="checkbox"/>	-
3q Restlessness / fidgetiness	-	-	-	-	-	<input type="checkbox"/>	-
3r Impulsivity	-	-	-	-	-	<input type="checkbox"/>	-
3s Eating difficulties	-	-	<input type="checkbox"/>	-	-	-	-
3t Sleeping difficulties	-	-	<input type="checkbox"/>	-	-	-	-
6a Reading difficulties	-	-	-	-	-	-	<input type="checkbox"/>
6b Writing difficulties	-	-	-	-	-	-	<input type="checkbox"/>
6c Spelling difficulties	-	-	-	-	-	-	<input type="checkbox"/>
6d Mathematics difficulties	-	-	-	-	-	-	<input type="checkbox"/>
7c Neuropsychological attention deficits	-	-	-	-	<input type="checkbox"/>	-	-
7d Dual-tasking / multi-tasking difficulties	-	-	-	-	<input type="checkbox"/>	-	-
7e Memory difficulties	-	-	-	-	<input type="checkbox"/>	-	-
7f Visuo-spatial difficulties	-	-	-	-	<input type="checkbox"/>	-	-
7g Executive difficulties	-	-	-	-	<input type="checkbox"/>	-	-
7h Disorientation	-	-	-	-	<input type="checkbox"/>	-	-

## 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	<input type="checkbox"/>	
8.1b Stress in family	<input type="checkbox"/>	
8.1c Stress in sibling relationships	<input type="checkbox"/>	
8.1d Parent-child relationship difficulties	<input type="checkbox"/>	
8.1e Parent-parent/partner relationship difficulties	<input type="checkbox"/>	
8.1f Difficulty connecting in community	<input type="checkbox"/>	
8.1g Difficulties in career	<input type="checkbox"/>	
8.2a Low self-esteem		<input type="checkbox"/>
8.2b Stress in family		<input type="checkbox"/>
8.2c Stress in sibling relationships		<input type="checkbox"/>
8.2d Parent-child relationship difficulties		<input type="checkbox"/>
8.2e Parent-parent/partner relationship difficulties		<input type="checkbox"/>
8.2f Difficulty connecting in community		<input type="checkbox"/>
8.2g Difficulties in career		<input type="checkbox"/>

\*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.



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Thank You!