

TSC Learning and Behaviour Questionnaire

This questionnaire asks families and people who live with tuberous sclerosis about clinical services for some of the problems associated with TSC. The focus is on learning, behavioural, mental health and educational difficulties. This includes challenging behaviours, autism, ADHD, depression, anxiety, learning disability, specific learning problems etc.

Please fill out this blue sheet if you care for someone with TSC, and return it to the TSA by **15 September** in the envelope provided.

Please note: The green sheet is for people who have TSC themselves.

Remember: 'Problems' refers to learning, behaviour, mental health, education/job difficulties

1. How old is the person with TSC? Years

2. Are they? Male Female

3. Which part of the country do they live in?

England: South & London England: North England: Midlands & East
 Wales Scotland Northern Ireland

4. How able are they in terms of their learning?

Normal Intelligence Learning Disability Mild/Moderate Learning Disability
 Severe/Profound Learning Disability

5. Do you have concerns about their problems?

Yes, current concerns Yes, but not currently No

6. Have you had help or support for these problems (learning, behaviour, mental health, education)?

Yes No (If no, please go to Question 11)

7. If yes, who gave help?

GP Paediatrician Neurologist Psychiatrist
 Psychologist School Other (please state)

8. Was the help through a specialist TSC clinic?

Yes No (If no, please go to Question 10)

9. If yes, which clinic?

10. How helpful have you found this support?

Very helpful A little Not a lot Not at all

11. What sort of help would you ideally like for these type of problems?

12. There are recommended assessments for all people with TSC (Clinical Guidelines 2003). Did your child/family member have these assessments, as far as you know?

Yes Only some No Don't know about these guidelines

13. How easy is it for you to access help for your child/family member where you live?

Easy Very Easy Difficult Very Difficult

14. Would you be willing to travel to a clinic which specialises in learning and behaviour?

Yes No

15. What is the biggest problem that you would like to have help for?

16. Any other comments or suggestions:

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Thank you!

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1. How old are you? Years

2. Are you: Male Female

3. Which part of the country do you live in?

England: South & London England: North England: Midlands & East
 Wales Scotland Northern Ireland

4. How able are you in terms of learning?

No learning problems Some learning problems Lots of learning problems

5. Do you have worries about your problems?

Yes, current concerns Yes, but not right now No

6. Have you had help or support for these problems (learning, behaviour, mental health, education)?

Yes No (If no, please go to Question 11)

7. If yes, who gave you help?

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Easy Very Easy Difficult Very Difficult

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Yes No

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16. Any other comments or suggestions:

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Thank you!