

## **A Questionnaire about Mental Health Services for Parents/Carers of an Adult with an Autism Spectrum Condition\* who live in East Lancashire**

### **Instructions**

This questionnaire is to provide feedback to East Lancashire Primary Care Trust about what experiences adults with Autism Spectrum Conditions have had when accessing Mental Health services.

The answers that you give on the questionnaire will be kept anonymous; all of the responses received will be used to write a report advising the Primary Care Trust about what kinds of difficulties adults have accessing services, and how mental health services can be improved when providing support for adults with Autism Spectrum Conditions. If you would like further information about this assessment before you decide whether to complete the questionnaire, please read the participant information sheet.

Please answer all questions that apply to you.

If you require assistance completing the questionnaire or would like to give feedback to the project but are not able to complete the questionnaire, please contact Emma by phone on 01282 415455 or by email at [emma@actionasd.org.uk](mailto:emma@actionasd.org.uk) to organise an alternative method of feedback.

*\*Also known as Autism Spectrum Disorder, Autism Spectrum Condition is used here as this is preferred to the term Disorder. This can include Asperger Syndrome, High Functioning Autism, Pervasive Development Disorder Not Otherwise Specified, or suspected Autism without yet having a diagnosis.*

## **About You**

What Village, Town or City do you live in? \_\_\_\_\_

What is your date of birth? \_\_\_\_\_

What is your gender? Male  Female  Other (please tell us)

Which of the following best describes your current work/education status? (Please tick all that apply to you)

- Full-time employment
- Part-time employment
- Voluntary Work
- Full-time education
- Part-time education
- Not in any employment or education
- Other (please state) \_\_\_\_\_

Which of the following social activities do you participate in? (Please tick all that apply to you)

- Go to the pub with family or friends
- Go to the cinema with family or friends
- Play sports (please tell which sports) \_\_\_\_\_
- Go to parent/carers group or social evening
- Go to non-specific support group or social evening
- Online Forums
- Other (please state) \_\_\_\_\_

Do you feel that being a carer restricts your ability to participate in social activities?

- Yes
- No

**About the person you care for**

**1. How many Adults with an ASC do you care for?**

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**2. What is your relationship to the person/people that you care for?**

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**3. How long have you been providing care for them?**

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**4. How many hours each week do you usually provide care for them?**

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**5. Where does the person/people you care for live? (please tick all that apply)**

With you

In their own home

In supported living

In full residential Care

Other (please state)\_\_\_\_\_

**6. If known, how old was the person you care for when they got an ASC diagnosis?**

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**7. Were you involved in the process of trying to get a diagnosis for the person you care for?**

Yes

No

If yes, from start to finish how long did it take for them to get an ASC diagnosis?

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**About the person you care for**

**8. Which of the following best describes the ASC diagnosis of the person/people you care for? (Please tick all that apply to them)**

- Autism
- High Functioning Autism
- Asperger Syndrome
- Not yet diagnosed
- Other (please state) \_\_\_\_\_

**9. Do they also have a diagnosis of a mental health condition or a specific learning difficulty?**

- Yes
- No

If yes, please tick all that apply to them

- ADHD
- Dyslexia
- Dyscalculia
- Anxiety
- Depression
- Bi-polar
- Personality Disorder
- Other (please state) \_\_\_\_\_

*All further questions about diagnosis refer to their ASC Diagnosis*

**10. Did they receive a diagnosis through: (please tick one box)**

- An NHS practitioner
- A private Practitioner
- Other (please tell us): \_\_\_\_\_

**About the person you care for**

**11. Where did they go to get a diagnosis? (please tick one box)**

In East Lancashire

Outside of East Lancashire (please state which area): \_\_\_\_\_

**12. Was it necessary to pay to get the diagnosis? (please tick one box)**

Yes

No

(Optional) If yes, how much did it cost?: \_\_\_\_\_

**13. If the person you care for tried to get an ASC diagnosis as an adult was the process: (please tick one box)**

Easy

Difficult

Not possible

Other (Please state) \_\_\_\_\_

If it was difficult or not possible, what were the difficulties?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**14. Who takes responsibility for trying to access any services for the person with ASC?**

You

The person with the ASC

Other (please tell us): \_\_\_\_\_

If you have been involved in accessing services please answer the Access to Services Section, otherwise skip to question 21 about Mental Health Services for Adults with ASC's

**Access to Services**

**15. In the last 5 years have you tried to access any help or advice from a GP (General Practitioner) in relation to the person you care for and their ASC? (please tick one box)**

- Yes
- No

**If yes, was it: (please tick one box)**

- Easy
- Difficult
- Not possible
- Other (Please state) \_\_\_\_\_

What were the good or bad points about the experience?

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**16. In the last 5 years have you asked for a referral to mental health services for the person you care for through your GP? (please tick one box)**

- Yes
- No

**If yes, was it: (please tick one box)**

- Easy
- Difficult
- Not possible
- Other (Please state) \_\_\_\_\_

What were the good or bad points about the experience?

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**Access to Services**

**17. In the last 5 years have you asked for a referral to mental health services for the person you care for through other services (such as social services)? (please tick one box)**

- Yes
- No

**If yes, was it: (please tick one box)**

- Easy
- Difficult
- Not possible
- Other (Please state) \_\_\_\_\_

What were the good or bad points about the experience?

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**18. In the last 5 years have you tried to access any help or advice directly from mental health services for the person you care for? (Please tick one box)**

- Yes
- No

**If yes, was it: (please tick one box)**

- Easy
- Difficult
- Not possible
- Other (Please state) \_\_\_\_\_

What were the good or bad points about the experience?

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**Access to Services**

**19. In the last 5 years have you tried to access help or advice from Learning Disability Services for the person you care for? (please tick one box)**

Yes

No

**If yes, was it: (please tick one box)**

Easy

Difficult

Not possible

Other (Please state) \_\_\_\_\_

What were the good or bad points about the experience?

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**20. In the last 5 years have you tried to access help or advice from any private service providers for the person you care for? (please tick one box)**

Yes

No

**If yes, was it: (please tick one box)**

Easy

Difficult

Not possible

Other (Please state) \_\_\_\_\_

What were the good or bad points about the experience?

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**Support and Help that you need**

**24. What help or support do you and/or the person you care for receive from the NHS relating to their ASC (this can be by you visiting the hospital or people visiting you at home)?**

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**25. What help or support do you and/or the person you care for receive from Social Services relating to their ASC (this can be by you visiting the hospital or people visiting you at home)?**

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**26. Do you or the person you care for receive help or support from the NHS for any other issues? If so, please give brief details?**

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**27. Is there any form of support or help that you or the person you care for need from the NHS that you're not getting (if yes please state what type of support or help you need)?**

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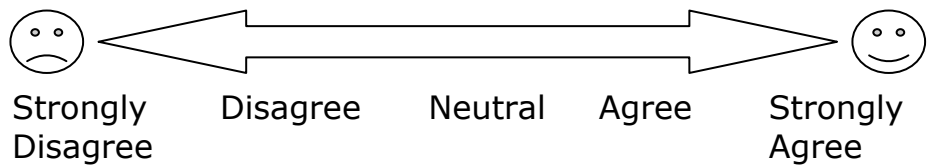
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## Your Opinions

Please read each of the following statements and indicate whether you Strongly Disagree, Disagree, are Neutral, Agree, Strongly Agree in the boxes next to the statement.



Mental Health Services in East Lancashire are accessible for adults with Asperger Syndrome

Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree

It is easy to get referred for an ASC diagnosis in East Lancashire

Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree

Mental Health staff in East Lancashire understand ASC's

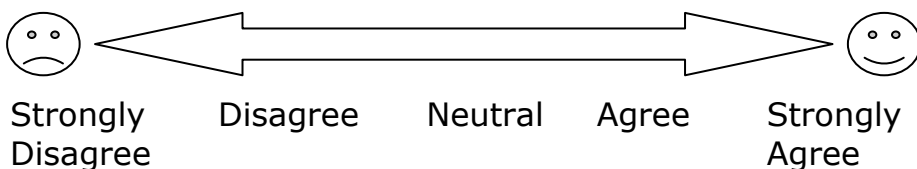
Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree

Current Mental Health Service provisions in East Lancashire are adequate for adults on the spectrum

Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree

All staff within mental health Services should receive autism awareness training

## Your Opinions



Training all staff within current services is the best way to improve services for adults with autism

Having one individual in each Mental Health Team who is skilled and experienced in Autism is the best way to improve services for adults with autism

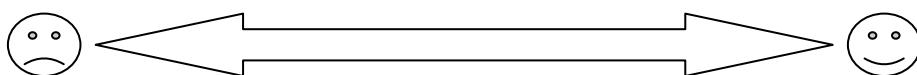
Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree

Providing specialist service for adults with autism to be referred to is the best way to improve services for adults with autism

Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree

## Your Opinions



Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree

I understand what Autism Spectrum Conditions are

Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree

Autism is a mental health condition

Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree

Autism is a learning disability

In addition to the questionnaire, further more in-depth feedback will be collected from May 2010 via methods such interviews, diary keeping and blogs, if you would like to be involved in giving further feedback please tick the box and provide contact details below:

Yes, I would like to be involved in giving further feedback

Name \_\_\_\_\_  
(Giving your name is optional but useful for when we contact you)

Email or phone number \_\_\_\_\_

Thank you very much for completing the questionnaire. If you have filled out the online version please now click to submit your response. If you have downloaded a word document please save a copy and email it to me at [emma@actionasd.org.uk](mailto:emma@actionasd.org.uk). If you have printed off the questionnaire and filled it out by hand please post it to me at Emma Dunn, Action for ASD, Suite 7 Kings Mill, Queen Street, Burnley, BB10 2HX.