

Supplementary Material: Copy of survey

Title: Talking about Autism: autistic parents' experiences of talking about autism with their children

Section One:

To start, we want to ask some questions about you...

Q1. Are you autistic?

- Yes (I have a formal diagnosis)
- Yes (I self-identify as autistic)
- No (I am not autistic)

[Skip To: End of Survey if selected]

Q2. Do you have at least one child on the autism spectrum who is under the age of 18 years?

- Yes
- No

[Skip To: End of Survey if selected]

Q3. Are you currently living in the United Kingdom?

- Yes
- No

[Skip To: End of Survey if selected]

Q4. How old are you?

[Drop down selection box including ages 18-70+]

Q5. What is your gender identity?

- Male (including transgender male)
- Female (including transgender female)
- Non-binary
- Other (please specify) _____

Q6. What is your ethnicity?

- White (including British, Irish, or any other White background)
- Black or Black British Caribbean (including Caribbean, African or any other Black background)
- Asian or Asian British (including Indian, Pakistani, Bangladeshi or any other Asian background)
- Chinese or any other ethnic group
- Prefer not to say
- Other (please give details) _____

Q7. Where in the UK do you live?

- East of England
- East Midlands
- London
- North East

- North West
- Northern Ireland
- Scotland
- South East
- South West
- Wales
- West Midlands
- Yorkshire and the Humber

Section Two:

Now we'd like to ask about your family (children and partner) ...

Q8. How many children (of any age) do you have?

[Drop down selection box including 1-7+ children]

Q9. How many of your children (of any age) are on the autism spectrum?

[Drop down selection box including 1-7 children]

Q10. In what order did your family receive their autism diagnoses? (e.g., 1. My first child, 2. My partner, 3. My third child)

Q11. Do your children (autistic or non-autistic) know about *your* autism diagnosis?

Yes (Please tell us more about this if you would like)

No (Please tell us more about this if you would like)

It's complicated (Please explain)

Section Three:

Now we'd like to ask about your eldest child (under the age of 18 years) on the autism spectrum.

Q12. What is your child's gender identity?

Male

Female

Other (please give details) _____

Q13. How old was your child when they received their autism diagnosis?

[Drop down selection box including 0-18 years old]

Q14. How old is your child now?

[Drop down selection box including 0-18 years old]

Q15. What is your child's diagnosis?

- Autism
- Autism spectrum disorder/condition
- Asperger's syndrome/disorder
- High-functioning autism
- Pervasive Developmental Disorder – Not Otherwise Specified
- Other (please give details) _____

Q16. Does your child have any other diagnoses? (Please choose all that apply)

- No
- A physical disability (including epilepsy and hearing or vision impairment)
- A learning disability (including dyslexia)
- An intellectual disability
- An affective condition (including depression and anxiety)
- A behavioural condition (including ADHD, conduct disorder, Tourette syndrome)
- A mental health condition (including bipolar disorder, OCD, schizophrenia)
- A genetic condition (including Fragile X syndrome)
- Any other condition (please give details) _____

Q17. Describe your child's use of spoken language.

- Language use is completely typical
- There are difficulties mainly with "pragmatic (i.e., social) language"
- Little or no spoken language

Q18. If you would like to tell us more about this, please do so in the box below.

Q19. Where has your child received the majority of their education?

- Mainstream school
- Specialist unit/base within a mainstream school
- Specialist school
- Home school
- Not applicable
- Other (please give details) _____

Section Four:

*Now we'd like to ask about if/how your child found out about their autism diagnosis. (If you have more than one autistic child, please tell us about your experiences with your **eldest** child under the age of 18 years.)*

Q20. Does your child know about their autism diagnosis?

- Yes, I told them
- Yes, someone else told them
- Yes, I think they know (but I haven't actually told them)
- No, they do not know (or do not understand)

Q21. If you would like to tell us more about this, please do so in the box below.

Q22. How satisfied were you with the way in which your child's diagnosis was disclosed to them? Please note: we are interested in how your child's diagnosis was explained to them, not the diagnostic process overall.

[Only display this question if the participant selected "Yes, I told them or "Yes, someone else told them" in response to Q20]

- Extremely satisfied
- Somewhat satisfied
- Neither satisfied or dissatisfied
- Somewhat dissatisfied
- Extremely dissatisfied

Q.23 Do any of your other autistic children know about their diagnosis?

- Yes, I told them
- Yes, someone else told them
- Yes, I think they know (but I haven't actually told them)
- No, they do not know (or do not understand)
- I do not have any other autistic children

Q24. If you would like to tell us more about this, please do so in the box below.

Q25. How satisfied were you with the way in which your child's diagnosis was disclosed to them?

[Only display this question if the participant selected "Yes, I told them or "Yes, someone else told them" in response to Q23]

- Extremely satisfied
- Somewhat satisfied
- Neither satisfied or dissatisfied
- Somewhat dissatisfied
- Extremely dissatisfied

Q26. Was there anything that was particularly *positive/helpful* about these discussions?

[Only display this question if the participant selected "Yes, I told them or "Yes, someone else told them" in response to Q20 and/or Q23]

Q27. Was there anything that was *negative/unhelpful* about these discussions? Or perhaps something that you felt could have been done better/differently?

[Only display this question if the participant selected “Yes, I told them or “Yes, someone else told them” in response to Q20 and/or Q23]

Section Five:

Q28. Did you receive any support in talking to your children (autistic or non-autistic) about autism?

- Yes
- No

Q29. How useful was this support?

[Only display this question if the participant selected “Yes” in response to Q28]

- Extremely useful
- Very useful
- Moderately useful
- Slightly useful
- Not at all useful

Q30. Would you like to have any support in talking to your children about autism?

[Only display this question if the participant selected “No” in response to Q28]

- Yes
- Maybe
- No

Q.31 If you would like to tell us more about this, please do so in the box below.

Section Six:

Now, we’d like to ask you about your day-to-day conversations with your children (both autistic and non-autistic) about autism.

If you have autistic and non-autistic children, we’re especially interested in learning whether there is anything different about the way you talk to your autistic and non-autistic children.

Q32. If you talk about autism with your children, what kind of things do you talk about? If you prefer, please give an example of a particular discussion you had about autism with your child.

Q33. Which terms do you use when talking about autism in your family? (Please choose all that apply)

- Person with autism
- Has autism
- Autistic person
- Autistic
- On the autism spectrum
- On the autistic spectrum
- Autism spectrum disorder
- Autism spectrum condition
- High-functioning
- Low-functioning
- Asperger syndrome
- Has Asperger syndrome
- Aspergic
- Aspie

Q34. Is there anything else you'd like to tell us about the terms you use to talk about autism?

Q35. Is there anything particularly *positive* about your discussions about autism that you can tell us about?

Q36. Is there anything you feel could be done *better/differently* regarding your discussions about autism with your children?

Q37. Has your experience as an autistic person (and learning about your own diagnosis) influenced the way you talk to your children about autism? If so, how?

Q38. What advice would you give to other parents (autistic or non-autistic) who want to talk to their children about autism?

Q39. Before we end the survey, is there anything further you would like to add about your experiences?

- End of Survey -