

Results of survey undertaken by parents/carers of young people aged 14-25 with Autism/Asperger's

Introduction:

This survey was undertaken in January 2016 and was available for a period of 4 weeks. Parents/carers were able to access this electronically through Stockport Council website and responses were collated and analysed using 'Snap' survey. Hard copies were also made available. The survey was promoted through Stockport Council's social media and through a variety of networks and distribution lists.

Feedback was taken from 2 groups of parent/carers:

- For those with young people aged 14-17, we wanted to know what would best help parents/carers to support their child as they prepare for adulthood.
- For those who are still supporting young adults aged 18-25, we wanted to know what have their experiences of services been like and what could have made that journey better?

Parents/carers were asked to complete one response for each child or just do the survey once. The reason for the survey was to help inform Stockport Council how young people and their families can be best supported as they move from childhood into adulthood, and so that they can prepare for independence wherever possible. The aim is to make sure that fewer young adults find themselves in crisis once they have made that leap into independence. The survey was developed in partnership with parent/carer groups in Stockport.

Results:

The results were collated on 23/2/2016 and were used to write this report. Responses are given as percentages and actual numbers are in brackets.

This section was answered by all respondents (N=62)

Q1. Are you a parent/carer of a young person with Autism/Asperger's?

- Yes – 100% (62)

Q2. Has there been a professional diagnosis?

- Yes – 94% (58)
- No – 6% (4)

Q3. Does your child have any other diagnosed conditions? For example....

- Dyspraxia – 15% (9)
- Dyslexia- 10% (6)
- Pervasive Development Disorder (PDD) – 3% (2)
- Learning Disability – 20% (12)
- Other (please specify) – 28% (17)
- Not applicable – 34% (20)

Parents/carers described other conditions as a single or combination of the following: Generalised anxiety disorder, uneven cognitive profile and emotional regulation difficulties / ADHD/Mental health issues: depression/Epilepsy/Tourette's Syndrome/ Nystagmus (visual impairment)/motor restlessness/visual tracking difficulties, Developmental Delay/Auditory processing disorder/ stammer/Speech and language/Cerebral palsy

Q4. How many children do you have with Autism/Asperger's?

- 1 = 81% (50)
- 2 = 18% (11)
- 3 = 2% (1)
- More than 3 = 0

Q5. What is the gender of the child in question?

- Male – 73% (45)
- Female – 17% (17)

Q6. Age/s of your child/children?

- 14-15 years – 38% (22)
- 16-17 years – 28% (16)
- 18 – 21 years – 24% (14)
- 22-25 years – 10% (6)

This section was answered by parents/carers of 14-17 year olds (N=38)

Q7. Which services are currently involved with you and your child? (Please tick all that apply)

- School/Education = 95% (35)
- Health therapies (Speech & Language, OT, Physio) = 19% (7)
- Health, CAMHS = 38% (14)
- Health, other = 16% (6)
- Social care = 19% (7)
- Voluntary Organisation = 14% (5)
- Other* = 11% (4)

*Note: services identified as 'other' would fit into other named categories

Q8. Does your child have an Education, Health & Care (EHC) plan, statement or Learning Disability Assessment (LDA)?

- Yes – 71% (27)
- No – 24% (9)
- Not sure – 5% (2)

Q9. If your child is not on a plan, are they receiving additional support in school/education? (This is known as SEN support, was previously known as school action / action plus or on an Individual Education Plan – IEP)

- Yes – 41% (7)
- No – 53% (9)
- Not sure – 6% (1)

Q10. Have you had the opportunity to discuss options for post 16 education/employment?

- Yes – 42% (16)
- No – 58% (22)

Q11. Does your child have a package of care from (please tick all that apply)

- Health – 50% (3)
- Social Care – 83% (5)

Q12. Does your child have a personal budget?

- Yes – 6% (2)
- No – 94% (34)

Q13. Have discussions taken place yet to consider these post 18?

- Yes – 0
- No – 100% (38)

Q14. Thinking about your child becoming an adult at 18, what information would you find most helpful? (Please tick all that apply)

- Support networks for young people – 82% (31)
- Support networks for parents/carers – 45% (17)
- What post 18 services are available and how to access them – 90% (34)
- Criteria for personal budgets – 50% (19)

Q15. Is there anything else which you think would help 14-17 year olds and their parents/carers to prepare for the transition to adulthood?

The following comments have been summarised from all the feedback

- Services that can liaise with colleges and large employers
- More information on different options and also benefits advice
- Actual information – so I can get answers
- Having a named organization to go to for help
- Some idea of where to go for help
- Social clubs, making friends, talks for young children
- A contact person that knows your child
- A central contact to ask who we can ask about any question and then we know which organisation can help with specific questions
- Run courses on the PIP and what the budget can be used towards
- Careers advice for the young person, especially explaining, maybe using a flowchart or other visual means, what education route needs to be taken to achieve a particular career.
- Social skill sessions, tailor made depending on whether the young person is going into employment or onto further education. Organisational skills training! Basics like how to arrive on time, how to organise your time.
- An statutory annual review system in colleges
- Information on promoting independent living.
- Information about financial support and the options for continuing in full time education.
- Understanding how my child will be supported to gain work related skills.
- Understanding how the transition to employment is managed and what support is available to help them find paid work
- More resources so that cut off for support doesn't happen at 15
- Help with strategies for everyday living skills
- Better working relationships between school, parents and other services
- Clarity about the criteria for CAMHS and it's role

The following section was answered by parents/carers of 18-25 year olds N=20

Q16. Which services are currently involved with you/your son/daughter? (Please tick all that apply)

- Education = 35% (7)
- Employment = 15% (3)
- Health – Therapies (Speech & Language, OT, Physio) = 10% (2)
- Mental Health = 30% (6)
- Health, other – 5% (1)
- Voluntary organisation – 15% (3)
- Other* = 10% (2)
- None of the above = 35% (7)

*Note: services identified as 'other' would fit into other named categories

Q17. Does your son/daughter have an Education, Health & Care (EHC) plan, statement or Learning Disability Assessment (LDA)?

- Yes – 45% (9)
- No – 45% (9)
- Not sure – 10% (2)

Q18. Does your son/daughter receive a package of care from (please tick all that apply)

- Health – 13% (1)
- Social Care – 88% (7)

Q19. Does your son/daughter have a personal budget?

- Yes - 50% (10)
- No – 50% (10)

Q20. What was most helpful during your transition period?

Response → Question ↓	Strongly agree	Somewhat agree	Neither agree or disagree	Somewhat disagree	Strongly disagree	Don't know
Staff were knowledgeable	11% (2)	11% (2)	6% (1)	22% (4)	44% (8)	6% (1)
We received sufficient information to enable my son/daughter to make choices	11% (2)	22% (4)	0	11% (2)	50% (9)	6% (1)
The information we received was timely	6% (1)	6% (1)	6% (1)	27% (5)	44% (8)	11% (2)
We were kept up to date and informed of progress	0	39% (7)	0	11% (2)	50% (9)	0
We felt listened to	6% (1)	22% (4)	6% (1)	11% (2)	55% (10)	0
Our views were taken into account when decisions were being made	6% (1)	28% (5)	11% (2)	17% (3)	38% (7)	0
We are confident that our son/daughter will be able to live independently (with support where appropriate)	11% (2)	16% (3)	0	26% (5)	37% (7)	11% (2)

Q21. Is there anything else which you think would have helped you and your son/daughter to prepare for the transition to adulthood?

The following comments have been summarised from all the feedback

- Better relationships with parents, involving them in decision making and staff having a more person centred approach
- Support following diagnosis – for the young person and the parents so that they can understand
- Better pathway planning into Adult Services – for those who are eligible
- Peer support – for the young person and the parents
- Better choice of work related options such as apprenticeships/work experiences for those with Asperger's
- Mentoring/befriending schemes
- Better information on Stockport services

- Support to find jobs, help with applications, CVs, interview skills, social skills
- Better understanding by staff, including schools, of the condition, it's impact on families and how to offer appropriate support
- Engagement of council staff to support transition during high school
- Information about what support is available
- A better informed workforce so that they can signpost parents to support

This section was answered by all respondents (N=62)

Q22. Are you aware that young people over 16 now have the right to make decisions about their future, independent of their parents/carers?

- Yes – 71% (44)
- No – 29% (18)

Q23. Are you aware that information is available on the SMBC website?

- Yes – 31% (19)
- No – 69% (42)

Please provide your postcode:

SK1	SK2	SK3	SK4	SK5	SK6	SK7	SK8	Other
3	8	7	6	5	5	13	11	2

Next steps:

- Survey to be published on the Local Offer webpages
- 34 parents/carers provided their contact details in order to be involved in future developments.
- Feedback and further discussion opportunities will be offered in the Autumn term.

If you have any queries regarding this survey, please contact Helen Hayes, helen.hayes@stockport.gov.uk