

Appendix 4: Questionnaire for parents and carers of children and young people with AS



Questionnaire for Parents and Carers of Young People (10-18 years) with Asperger Syndrome Living in Northern Ireland

Introduction

The Northern Ireland Commissioner for Children and Young People (NICCY) has commissioned a Review of needs and services for 10-18 year olds who have been, or are currently in the process of being, diagnosed with Asperger Syndrome.

The Review is being undertaken by a team from the University of Birmingham.

We would like to hear YOUR VIEWS on the help and support you have received so far. In particular, we would like to know what you feel has been helpful to you and your child/children, what might be improved and what the gaps in provision are.

How to Get Involved

Please answer the questions below, if they are relevant to you.

We know that some families have more than one child with Asperger syndrome. If this is true for you, can you please fill in a separate questionnaire for each child in your family with Asperger syndrome?

When you have completed the questionnaire, please return it **by post to:**
Dr Glenys Jones, School of Education, University of Birmingham, Edgbaston,
Birmingham, B15 2TT

Findings of the research

We will use what you, and others tell us, to write a report. Please note, we will not use your (or your child's) name in the report or any other information that would mean others could identify you. All those who complete and return a questionnaire will be sent a summary copy of the report (giving its main findings and recommendations) plus a list of references and resources on Asperger syndrome.

Statement of consent

I am happy to give my views to the Birmingham Team and for them to put these in their report to NICCY and to use when they are teaching other people about Asperger syndrome, provided no names of places or people are mentioned and the source of the information is not given.

Signed: _____ Date: _____

Further Information

If you have any questions or want any support in completing this questionnaire, please contact Glenys Jones. Her email address is Asperger@contacts.bham.ac.uk; her telephone number is 0121 414 5620 or 0121 414 7102

Many thanks

SHORT QUESTIONNAIRE

SECTION A:

DETAILS OF THE PERSON(S) FILLING IN THIS QUESTIONNAIRE

Note: If you do not want to give your name(s), then please leave these details out.

1 Your last name: _____ Your first name: _____

2 Relationship to the child with Asperger syndrome:
(e.g. mother; father; grandmother; stepmother; foster parent)

3 Area in which you live in Northern Ireland (please tick):

Region	Please tick where you live
Belfast	
North Eastern	
South Eastern	
Western	
Southern	

4 Approximately, how long have you lived in this area?
_____ years

5 If less than 5 years, where have you lived before?

SECTION B:

DETAILS ABOUT YOUR CHILD WITH ASPERGER SYNDROME

(If you have more than one child with Asperger syndrome, please fill in a separate questionnaire for each child).

1 Name of your child (optional): _____

2 Initials of first name and family name of your child:
(e.g. if Ben Jones, write BJ)

3 Sex of your child (please circle): Male Female

4 Date of birth of your child: _____

5 Age of your child now: _____years

6 Present diagnosis (please circle):

Asperger syndrome / High functioning autism/ Other, please state:

7 Does your child have any other diagnoses or conditions?
(e.g. epilepsy; ADHD; dyslexia; dyspraxia; hearing impairment)

YES NO

If YES, give brief details:

8 Are there any other children in the family living at home?

NO

YES, there are _____ other children living at home

SECTION C: SUPPORT AND SERVICES RELATING TO DIAGNOSIS

1 Approximate age of your child when first diagnosed with Asperger syndrome: _____years

2 ON THE WHOLE, how satisfied were you with the diagnostic process in terms of the following:

Very satisfied Quite satisfied Not very satisfied Not at all satisfied

Please comment further if you wish:

SECTION D: SUPPORT FROM EDUCATION and SCHOOLS/COLLEGES

- 1 Which type of school/College does your child attend at present?
(please tick)

Ordinary mainstream in our home area	
Ordinary mainstream outside our home area	
Special unit or class in a mainstream school	
Special school for children with moderate learning difficulties	
School for children with social, emotional and behavioural difficulties	
Special school for children with severe learning difficulties	
Special school for children with autism and Asperger syndrome	
Communication or Language Unit	
Home educated	
No education at present	
Other, please specify	

- 2 What is the name of the school/College (optional)?

- 3 How far is your child's current school/College from your home?
(please tick)

DISTANCE FROM HOME	TICK THE DISTANCE FROM HOME
Walking distance	
1 to 3 miles	
5-10 miles	
11 to 20 miles	
20-40 miles	
over 40 miles from home	

- 4 How does s/he usually get to school/college (e.g. walks; parents car; taxi; public bus)?

- 5 If over 40 miles, please state approximately how many miles from home, and in which area of Ireland or the UK this is.

6 On the whole, how satisfied are you with your child's current school /College and educational support and advice? (PLEASE CIRCLE)

Very satisfied Quite satisfied Not very satisfied Not at all satisfied

Please comment further if you wish:

7 If your child is 14 or over, have you had any advice from the Careers Advisers?

YES NO Not applicable

SECTION F: SUPPORT FROM HEALTH AND SOCIAL SERVICES

1 Please tick in the boxes below, the type of support/advice you and/or child has had from professionals working in HEALTH and SOCIAL SERVICES, and rate how useful this has been

Type of help	Not received	Very useful	Quite useful	Not very useful	Not at all useful
Individual counselling					
Medication for anxiety/depression					
Medication for over-activity					
Befriender					
Asperger support group for children/young people					
Parent support group					
Short-term overnight care					
Activities organised					
Financial allowances					
Literature to read					
Support/advice for brothers and sisters					
Other, please specify					
Other, please specify					
Other, please specify					
Other, please specify					

Please comment further on these if you wish:

2 Can you comment on the extent to which the following health professionals appear to have understood the particular needs of your child in relation to Asperger syndrome

Professional	Very good understanding	Quite good understanding	Not very good understanding	Appeared to have no understanding	Not seen
Dentist					
Health visitor					
GP					
Hospital nurse					
GP receptionist					
Optician					
School nurse					
Hospital doctor					
Orthodontist					
Physiotherapist					
Speech and language therapist					
Occupational therapist					
Clinical psychologist					
Paediatrician					

SECTION G: SUPPORT FROM VOLUNTARY AGENCIES, INCLUDING AUTISTIC SOCIETIES

1 Please tick in the boxes below, the type of support/advice you and/or child has had from VOLUNTARY AGENCIES INCLUDING AUTISTIC SOCIETIES AND GROUPS, and rate how useful this has been

Type of help	Not received	Very useful	Quite useful	Not very useful	Not at all useful
Individual counselling					
Befriender					
Asperger support group for children/young people					
Parent support group					
Activities organised					
Financial help					
Literature given					
Support/advice for brothers and sisters					

Other, please specify					
Other, please specify					
Other, please specify					
Other, please specify					

Please comment further on these if you wish:

SECTION H: FINAL SECTION

1 Looking back over the years what has been the most helpful in terms of the support YOU in relation to your child with Asperger syndrome, and why?

2 What is your biggest problem/concern in living with your child with Asperger syndrome at present?

3 On a scale of 1 to 10, how do you feel today about the help and support you are receiving (1 is very satisfied)

1 2 3 4 5 6 7 8 9 10

very satisfied

not at all satisfied

With many thanks for your views and time, from staff at NICCY and the Birmingham Team.

If you would be happy for the Team to contact you to discuss any of the issues you have mentioned in this Questionnaire, please give your email and/or telephone number below:

My email address is: _____

My telephone number is: _____