



## Regional Consultation

# Your Views Count

## Carers' Questionnaire

For families of children/young people with  
autistic spectrum disorders living in the  
West Midlands



- 1 **Birmingham**
- 2 **Coventry**
- 3 **Dudley**
- 4 **Sandwell**
- 5 **Solihull**
- 6 **Walsall**
- 7 **Wolverhampton**
- 8 **Staffordshire**
- 9 **Stoke-on-Trent**
- 10 **Herefordshire**
- 11 **Worcestershire**
- 12 **Shropshire**
- 13 **Telford and Wrekin**
- 14 **Warwickshire**

***Please invest your time and make a difference  
to pre-school to adolescent services  
in the West Midlands***

- **The questionnaire should be completed by people who are directly involved with the day-to-day care of the child/young person concerned – eg parents, foster carers, other carers (including grandparents) and siblings. The term ‘your child’ includes: son, daughter, brother, sister, grandson/daughter, etc.**
- **This questionnaire refers throughout to Autistic Spectrum Disorders/ASD. For ease of understanding, ASD is used to describe Autism, Asperger’s Syndrome and Semantic Pragmatic Language Disorder.**
- **This means that we might receive more than one questionnaire for each individual child/young person to reflect the fact that carers – eg the mother and father – might have different views. This is alright!**

- **If you feel that you cannot answer a particular question, simply miss it out and go on to the next.**
- **If you need help in completing the questionnaire, or there is something you do not understand, please contact either your Parent Partnership Service, the West Midlands Autistic Society or the West Midlands Regional Project.**

## Section 1

### Child’s/young person’s personal details

*We need to gather these personal details so that we can provide information about numbers, age and gender to Education, Health, Social Services and the Voluntary Sector to enable them to plan future provision and services. Names are optional, but if provided they will be treated with absolute confidence and will not be given to anyone without your permission.*

1. Name of the local authority where the child/young person lives:

2. Child’s/young person date of birth:

3. Gender: male/female

4. What is your relationship to the child/young person with autistic spectrum disorder?

5. Does your child/young person have a current diagnosis of ASD?

Yes     No

6. Was this the original diagnosis?

Yes     No

6a. If no, what was the original diagnosis?

## Section 2

### Diagnosis

**Note:** The term diagnosis is used to describe **the name** of the disability/learning difficulty that the child/young person has.

*We will use this information to make recommendations on: assessment and diagnosis, giving information and support for families and the co-ordination of services.*

#### 2.1 Before the diagnosis

1. Who was the first person to suspect that your child had an autistic spectrum disorder/special needs?

Please tick:

- a. You
- b. Another family member
- c. Health visitor
- d. General practitioner (GP)
- e. Playgroup leader
- f. Teacher
- g. Social worker
- h. Other (please specify)

2. What age was your child when you first became concerned?

## 2.2 Diagnosis

*Please complete this section only if the child/young person has a diagnosis of ASD. If not, then please go to Section 3.*

**3.** At what age was your child diagnosed?

**4.** Were you expecting this diagnosis?

Yes  No

**5.** Was the diagnosis confirmed in writing?

Yes  No

**5a.** If yes, by whom?

**6.** What was the diagnosis – eg Asperger's Syndrome, Autism?

**7.** Has your child had any other diagnosis – eg ADHD, dyspraxia?

## 2.3 What happened next?

*We will use this information to make recommendations on how services can be improved to support families from the moment at which they are given a diagnosis. This might, for example, include recommendations on the advice and information which is given to families.*

**8.** Please describe how you felt when you were told your child had an autistic spectrum disorder.

**9.** What help, support and information did you feel that you needed at the time of diagnosis?

**10.** Did you receive this support?

Yes  No

**10a.** If not, what support or other help were you offered?

**11.** Please give any additional comments that you might want to make about the way you were given the diagnosis.

**12.** To what extent do you feel that the information you gave was shared/co-ordinated between the agencies you were involved with?

**13.** Did you receive an explanation of Autistic Spectrum Disorder?

Yes  No

**13a.** If 'yes', from whom?

**14.** Did you have an opportunity to discuss the diagnosis?

Yes  No

**14a.** If 'yes', with whom?

**15. Did you receive:**

- **a. reading materials or other guidance on where to get further information?**

Yes     No

- **b. information on the Code of Practice (assessment/statements of special educational needs)?**

Yes     No

- **c. advice on the implications for education?**

Yes     No

- **d. advice/information on welfare benefits such as Disability Living Allowance?**

Yes     No

- **e. information on the availability of respite care/short-term breaks?**

Yes     No

- **f. advice on behaviour management**

Yes     No

- **g. support on helping brothers/sisters?**

Yes     No

- **h. Other (please specify)?**

Yes     No

**16. Please make any additional comments that you would like to make about your overall experience of the diagnostic process.**

**17. Have you found any of the following useful?**

	Yes	No
<b>a. Bookshops</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>b. Contact a Family</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>c. Educational psychologists</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>d. General practitioners</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>e. Health visitors</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>f. The Internet</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>g. The library</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>h. Local parents' support group</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>i. National Autistic Soc.</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>j. Paediatricians</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>k. Parent Partnership Services</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>l. Pre-school support workers</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>m. Social workers</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>n. West Midlands Autistic Soc.</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>o. Other (please specify)</b>	<input type="checkbox"/>	<input type="checkbox"/>

**18. Where do you feel that most of your support comes from?**

**a. Personal:**

**b. Professional:**

## Section 3

### Present: Education and education related provision

*We need to know how many children are placed in mainstream or special school provision and whether carers are satisfied with the choice of provision in their area. This information will be used to make recommendations on the development of provision across the West Midlands.*

**Please complete the appropriate section according to the child's/young person's age.**

- If your child attends pre-school provision, such as playschool/nursery, please go to **section 3.1**.
- If your child attends school, please go to **section 3.2**.
- If your child is educated at home, please go to **section 3.3**.
- If the young person is post 1 and has left school, please go to **section 3.4**.

#### 3.1 Pre-school

##### 1. My child attends:

- a. Mother and Toddler
- b. Playschool
- c. Child Development Centre
- d. Parent Centre
- e. Private day nursery
- f. Local authority mainstream nursery
- g. Local authority special needs nursery
- h. Other (please specify)

##### 2. S/he attends:

- a. part-time
- b. full-time
- c. split placement

Now please go to **section 3.5**.

#### 3.2 School

##### 3. My child attends:

- a. a mainstream school
- b. a mainstream resource base/unit
- c. a special school which caters for:
  - i. moderate learning difficulties
  - ii. severe learning difficulties

iii. Autism

iv. other (please specify)

##### 4. S/he attends as:

- a. a day pupil
- b. a weekly boarder
- c. a termly boarder
- d. a 52 week residential boarder
- e. other

##### 5. Please comment on whether these arrangements are convenient for the family.

##### 6. Does your child attend a private or independent school?

- Yes  No

##### 6a. If 'yes', would you please tell us why you chose a school in the private sector?

##### 7. Who funds the placement?

Now please go to **section 3.5**.

#### 3.3 Educated at home

##### 8. Is your child following a specific programme (eg Portage, Son-Rise Options or Lovaas)?

- Yes  No

##### 8a. If 'yes', which one?

9. How is this funded?

10. Who carries out the programme?

11. Do you think the programme meets your child's needs?

12. Do you have help from any professionals – eg educational psychologist, specialist teacher, speech and language therapist?

Yes  No

12a. If 'yes', from whom (please list)?

Now please go to **section 3.6**.

### 3.4 Post-16 – Further Education

13. The young person attends:

- a. a mainstream School
- b. a mainstream resource base/unit
- c. a special school which caters for:
- i. moderate learning difficulties
  - ii. severe learning difficulties
  - iii. Autism
- d. a mainstream college
- e. a specialist college
- f. other (please specify)

14. S/he attends as:

- a. a day student
- b. a weekly boarder

- c. a termly boarder
- d. a 52 week residential boarder
- e. other

Now please go to **section 4**.

### 3.5 School-based support

15. What support does your child receive at school?

16. Does your child have an Individual Education Plan?

Yes  No

16a. If 'yes', have you seen it?

Yes  No

17. Do you think this support meets your child's needs?

Yes  No

17a. If not, why not?

### 3.6 Statement of Special Educational Needs

18. Does your child have a Statement of Special Educational Needs?

Yes  No

If 'no', please go to **section 3.8**.

18a. If 'yes', in what year was the statement issued?

19. Does the statement reflect your child's needs?

20. Have you received the services that the statement lists?

Yes  No

### 3.7 Annual Reviews

21. If your child has a statement, it should be reviewed once a year. Did you know this?

Yes  No

22. Do you attend the annual review meetings?

Yes  No

22a. If 'no', is there a reason? (Please specify, then go to **section 3.8**)

23. Do you receive reports from professionals involved with your child before the meeting?

Yes  No

24. Are you asked to give your views before the meeting?

Yes  No

25. Was the meeting helpful?

Yes  No

26. Did you feel comfortable with the organisation of the meeting?

Yes  No

26a. If not, why not?

### 3.8 Starting/moving school(s)

27. Please comment on any changes/difficulties that your child has experienced after starting a new school.

28. Has your child ever had a break in their education, because they have been excluded or there has been difficulty in finding the right provision?

Yes  No

28a. If 'yes', how long were they out of education?

## Section 4

### Transport/travelling time

*We will share this information with local authorities to help them evaluate their transport policies for children with special educational needs.*

1. How far is your child's school/college from home?

2. How long does it take for your child/young person to travel to school/college?

3. If you would like to share any comments about transport, both good and bad, we would like to know what you think:

## Section 5

### Staff training

*'Staff' includes any member of the staff at your child's/young person's current placement – eg nursery nurse, class teacher, tutor, dinner lady, support assistant, etc. This information will be used by local education authorities to assure parents of the expertise of staff or to plan further training for staff.*

1. Have the staff had any training in working with young people with ASD?

Yes  No  Don't know

2. Have the staff had any previous experience in working with young people with ASD?

Yes  No  Don't know

3. Do you think that there is a general awareness about ASD in your child's/young person's current placement?

Yes  No  Don't know

# Section 6

## External support

*This information will be shared with Health, Social Services and Education, to assist their planning of joint co-ordinated services.*

### 6.1 Other agencies

**1.** Have you been offered access to other services from Health, Social Services and/or, Education, such as respite care/shared care, speech and language therapy or supported leisure experiences?

Yes     No

**1a.** If 'yes', please let us know what you think of them.

Please specify:

**Service:**

	Inadequate		Satisfactory		Excellent
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5

### 6.2 Support organisations/groups

**2.** The following organisations/groups support families of people with ASD. Are you aware of them? Please indicate with a 'Y' for 'yes' and an 'N' for 'no'.

**2a.** If 'yes', how did you hear about them and have you been in touch with them?

Name of organisation	Have you heard of them?	How did you hear about them? (eg friend, magazine, etc)	Have you contacted them?
<b>AFASIC</b>			
<b>Allergy Induced Autism</b>			
<b>Contact a Family</b>			
<b>LEA Parent Partnership Services</b>			
<b>Local Parent Support Group</b>			
<b>National Autistic Society</b>			
<b>PACE</b>			
<b>Peach</b>			
<b>Solihull SNAP</b>			
<b>Walsall Resource Centre</b>			
<b>West Midlands Autistic Society</b>			
<b>Other</b> (please specify)			

**2b.** If you have used their services, how useful was it to you?

Service:	Inadequate		Satisfactory		Excellent
	1	2	3	4	5
AFASIC	1	2	3	4	5
Allergy Induced Autism	1	2	3	4	5
Contact a Family	1	2	3	4	5
LEA Parent Partnership Services	1	2	3	4	5
Local Parent Support Group	1	2	3	4	5
NAS	1	2	3	4	5
PACE	1	2	3	4	5
Peach	1	2	3	4	5
Solihull SNAP	1	2	3	4	5
Walsall Resource Centre	1	2	3	4	5
WMAS	1	2	3	4	5
Other (please specify)	1	2	3	4	5

**3.** Do you belong to a support group(s)?

Yes  No

**3a.** If 'yes', which one(s)?

**3b.** If 'no', is there a reason why not – eg cost, travel?

## Section 7

### Advocacy

**1.** To what extent do you feel that your child's/ young person's views are taken into account when decisions are made?

	Inadequate		Satisfactory		Excellent
1	2	3	4	5	

**2.** To what extent do you feel that your views are taken into account by decision makers?

	Inadequate		Satisfactory		Excellent
1	2	3	4	5	

**3.** Are there any additional comments you would like to make?

## Section 8

### Beyond school

**1.** Are you aware of any future opportunities available when your child leaves school?

Yes  No

**2.** If your child is 12 or over, do you know about the arrangements that are in place for planning their future – eg Year 9 – Transitional Review Planning?

Yes  No

*If your child has a statement and is 14 or over, they should have had a post-14 Transitional Review meeting. This should involve you, your child and representation/information from Careers, Education, SSD and Health.*

**3.** Did you know this?

Yes  No

**4.** Has your child had a Transitional Review meeting?

Yes  No

**5.** Were you asked to give your views before the meeting?

Yes  No

**6.** Did you receive reports from professionals involved with your child before the meeting?

Yes  No

**7.** Did you attend the transitional review meeting?

Yes  No

7a. If not, why not?

7b. Who attended/provided information/advice?

8. Was the meeting helpful?

Yes  No

9. Did you feel comfortable with the organisation of the meeting?

Yes  No

9a. If not, why not?

10. What else would you have found useful?

11. Has a transitional plan been drawn up?

Yes  No

12. Have you received information on adult services?

Yes  No

## Section 9

### 9.1 Impact on family life

1. Did you have to give up your job(s) or reduce your hours of paid work to attend to your child's educational and other needs?

Yes  No

2. List in order the three greatest sources of stress in caring for your autistic child.

(eg managing uncontrollable behaviour; lack of sleep; problems caused for other brothers and sisters; provision of constant parental care; financial problems due to loss of income; getting the right advice on early intervention; obtaining a diagnosis; the formal assessment process; securing the appropriate SEN support from the LEA; social isolation; others)

1
2
3

### 9.2 Training for parents – developing skills and strategies for supporting your child

*This information will be used to make recommendations on future courses and professional support for families.*

3. Have you had any formal training?

Yes  No

3a. If 'yes', how did you find out about it?

4. Who paid for it?

5. Was it helpful?

6. What training/further training do you think you or members of your family would benefit from?

## Section 10

### The future

1. What are your concerns and fears for your child's future?

2. What are your aspirations and hopes for your child's future?

Child's/young person's name (optional):

Do you know if anyone else is submitting/has submitted a questionnaire **about the same child/young person**?

Yes     No

Have you received more than one copy of this questionnaire?

Yes     No

If 'yes', how many?

***Thank you for taking the time to complete this questionnaire.***

*We would be grateful if you would return it in the Freepost envelope provided. **YOU DO NOT NEED A STAMP.***

We may want to contact you again. If you are willing for us to do so, please complete your personal details below.

Name:

Address:

Telephone:

***This questionnaire was devised in partnership with the following groups. Please feel free to contact anyone on the list if you require support in completing the questionnaire:***

***Contact & Family (West Midlands)***

The Princess Royal Centre, 4 Church Road, Edgbaston, Birmingham B15 3TD.

**Contact:** Mandy Addenbrooke, Development Officer

**Tel:** 0121 455 0655

***Coventry Parent Partnership Service***

Prior Deram Walk, Canley, Coventry CV4 8FT.

**Contact:** Linda Daly, Co-ordinator

**Tel:** 024 7667 8365

***Dudley Parental Partnership Scheme***

7 Albion Street, Brierley Hill, Dudley, West Midlands DY5 3EE.

**Contact:** Elizabeth Attfield, Parental Partnership Development Officer

**Tel:** 01384 485450

***Solihull Special Needs Active Partnership (SNAP)***

St. Andrew's Church Centre, Pike Drive, Chelmsley Wood, Birmingham B37 7US.

**Contact:** Wendy Magee and Jane Stanfield, Project Co-ordinators

**Tel:** 0121 770 5462

***Walsall Parent Partnership Scheme***

Education Department, Civic Centre, Darwall Street, Walsall, West Midlands WS1 1DQ.

**Contact:** Angela Jackman, Parent Liaison Officer

**Tel:** 01922 652313

***Warwickshire Parent Partnership Scheme***

Community Education Development Centre, Woodway Park School, Wigston Road, Coventry CV2 2RH.

**Contact:** Sue Robus

**Tel:** 024 7665 5700

***West Midlands Autistic Society***

17b Fellows Lane, Harborne, Birmingham B17 9TS.

**Contact:** Lynn Plimley, Head of Children's Services

**Tel:** 0121 426 4225

***West Midlands Regional Co-ordination***

**Project** Room 231, New Council Offices, Earl Street, Coventry CV1 5RS.

**Contact:** Jeannette Essex and Annette English, Project Managers

**Tel:** 024 7683 1510

***Wolverhampton Parental Partnership Scheme***

The Jennie Lee Centre, Lichfield Road, Wednesfield, Wolverhampton WV11 3HT.

**Contact:** Wendy Wallis, Parent Partnership Officer

**Tel:** 01902 555900

***Worcester Parental Partnership Scheme***

PO Box 73, Worcester WR5 2YA.

**Contact:** Ann Birch and Kate Richmond, Parent Partnership Officers

**Tel:** 01905 766029

**CEDC**

*Widening opportunities for learning*



Edited and designed by CEDC  
(Community Education Development Centre)  
Coventry

**Tel:** 024 7665 5700

Registered Charity No 512702