



State of Sheffield Survey 2014

What this survey is about

This survey is aimed at parents and carers of children and young people (aged 0-25) with a disability or additional needs who live in Sheffield or access services in Sheffield. It has been compiled by the Sheffield Parent Carer Forum with funding from the government's Department for Education.

Your answers will help us gather the data we need to speak with a strong voice on your behalf. We will use the results to lobby for better services and to protect existing ones.

Please return to: **Freepost RTBJ-SHTR-RRGJ, Sheffield Parent Carer Forum, St. Mary's Church Community Centre, Bramall Lane, SHEFFIELD S2 4QZ** (no stamp needed). To enter our prize draw to win £50, £30 or £20, please include your name and contact details on a separate sheet of paper. Names will not be matched to responses.

The closing date is Wednesday 30 April 2014. Thank you for taking the time to help us!

About you

We need to ask you a few questions about yourself. This will tell us whether our sample is representative of Sheffield's wider parent carer population.

1. Please state the first part of your postcode (e.g. S35):

2. Please state your gender: Female Male

3. Please state your ethnic group:

- | | | |
|--|---|---|
| <input type="checkbox"/> White British | <input type="checkbox"/> White and Asian | <input type="checkbox"/> African |
| <input type="checkbox"/> White Irish | <input type="checkbox"/> Any other mixed background | <input type="checkbox"/> Any other black background |
| <input type="checkbox"/> Any other white background | <input type="checkbox"/> Indian | <input type="checkbox"/> Chinese |
| <input type="checkbox"/> Traveller of Irish heritage | <input type="checkbox"/> Pakistani | <input type="checkbox"/> Yemeni |
| <input type="checkbox"/> Gypsy | <input type="checkbox"/> Bangladeshi | <input type="checkbox"/> Any other ethnic group |
| <input type="checkbox"/> White and black Caribbean | <input type="checkbox"/> Any other Asian background | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> White and black African | <input type="checkbox"/> Caribbean | |

4. Is English your first language? Yes No

5. Do you have a disability or long-term illness yourself? Yes No

6. How many children and young people (0-25 years) are part of your household?

7. How many of these children/young people have a disability or additional needs?

8. Do you also provide care for an adult aged 25+? (e.g. elderly parent, disabled partner). Yes No

9. In relation to your child with a disability/additional needs, please indicate if you are:

a lone parent a foster carer an adoptive parent a kinship carer (e.g. grandparent carer)

10. Are you a member of the Sheffield Parent Carer Forum? Yes No

About your child with a disability/additional needs

We need to ask you a few questions about your child with a disability/additional needs. This will tell us whether our sample is representative of Sheffield's child population. If you have more than one child with a disability/additional needs, it would be great if you could fill in one questionnaire per child. If that takes too much time, **please complete the questionnaire in relation to the child who is most severely affected.**

11. How old is your child with a disability/additional needs?

<input type="checkbox"/> 0-4 years	<input type="checkbox"/> 5-10 years	<input type="checkbox"/> 11-15 years	<input type="checkbox"/> 16-18 years	<input type="checkbox"/> 19-25 years
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12. How would you describe your child's disability/additional needs? Please tick all that apply.

<input type="checkbox"/> ADHD/ADD	<input type="checkbox"/> Multi-Sensory Impairment (vision & hearing)
<input type="checkbox"/> Autistic Spectrum Disorder	<input type="checkbox"/> Physical Disability/Mobility issues
<input type="checkbox"/> Behavioural Emotional or Social Difficulties	<input type="checkbox"/> Profound and Multiple Learning Difficulty
<input type="checkbox"/> Down Syndrome	<input type="checkbox"/> Severe Learning Difficulty
<input type="checkbox"/> Hearing Impairment	<input type="checkbox"/> Specific Learning Difficulty (e.g. Dyslexia)
<input type="checkbox"/> Medical Needs or Long-term Illness	<input type="checkbox"/> Speech, Language and Communication Needs
<input type="checkbox"/> Mental Health Difficulties	<input type="checkbox"/> Visual Impairment
<input type="checkbox"/> Moderate Learning Difficulty	<input type="checkbox"/> Waiting for diagnosis

13. Does your child have problems with:

<input type="checkbox"/> Sleep	<input type="checkbox"/> Eating or drinking
<input type="checkbox"/> Continence/toileting	<input type="checkbox"/> Anxiety/depression
<input type="checkbox"/> Challenging behaviour	Other (please specify): <input type="text"/>

Your family life

14. Please tell us whether caring for a child with a disability/additional needs limits what you and/or your family can do together.

	Easy	A bit tricky	Difficult	Very difficult	Impossible
Visiting friends/family					
Having people round to our house					
Going out, e.g. for a meal or to the cinema					
Taking regular exercise					
Going out for the day					
Going on holiday					
Doing household chores					
Other/comments:					

15. How easy is it for you to access non-specialist leisure services with your child with a disability/additional needs in Sheffield?

	Very easy	Easy	Somewhat difficult	Very difficult	Impossible
Parks					
Museums/galleries					
Cinema					
Theatres					
Restaurants/cafés					
Sports (spectator)					
Sports (participant)					
Shopping					
Other/comments:					

16. As a family, do you feel included in:

	We are fully included	Not always	Seldom	We feel isolated
Local community / neighbourhood				
Wider Sheffield				
School attended by disabled child				

17. If you have other children, how does having a brother or sister with a disability/additional needs affect them? Please tick all that apply.

<input type="checkbox"/> They miss out on attention	<input type="checkbox"/> It has affected their mental health or emotional wellbeing
<input type="checkbox"/> They are actively involved in caring	<input type="checkbox"/> It has affected their achievement at school
<input type="checkbox"/> They have been bullied	<input type="checkbox"/> It has made them more considerate/patient/understanding
<input type="checkbox"/> They can't have friends over	<input type="checkbox"/> It hasn't really affected them
<input type="checkbox"/> They miss out on activities (e.g. sport clubs, Scouts/Guides, social events)	Other (please specify): <input type="text"/>
<input type="checkbox"/> Their sleep is disrupted	<input type="text"/>

18. Do you have time to look after yourself (relaxing, socialising, exercising etc.)?

<input type="checkbox"/> I look after myself well	<input type="checkbox"/> I rarely have time to spend on me
<input type="checkbox"/> I sometimes find time for myself	<input type="checkbox"/> I often neglect myself

19. Has caring for your child with a disability/additional needs affected your:

<input type="checkbox"/> Mental health	<input type="checkbox"/> Relationships
<input type="checkbox"/> Emotional wellbeing	<input type="checkbox"/> None of the above
<input type="checkbox"/> Physical health	Other (please specify): <input type="text"/>
<input type="checkbox"/> Sleep	<input type="text"/>

20. Overall, how well do you feel you are coping?

<input type="checkbox"/> Coping well	<input type="checkbox"/> Coping	<input type="checkbox"/> Struggling	<input type="checkbox"/> Not coping
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21. Who provides practical and/or emotional support for you in your caring role? Please tick all that apply.

<input type="checkbox"/> Spouse/partner	<input type="checkbox"/> Portage Service
<input type="checkbox"/> Relatives	<input type="checkbox"/> Parent Partnership Service
<input type="checkbox"/> Friends	<input type="checkbox"/> Parents as Carers Advice Service
<input type="checkbox"/> Sheffield Parent Carer Forum	<input type="checkbox"/> MAST (e.g. Family Intervention Worker)
<input type="checkbox"/> Other parent support groups	<input type="checkbox"/> Social worker
<input type="checkbox"/> Counsellor	<input type="checkbox"/> Social Media (e.g. Facebook group)
<input type="checkbox"/> Health professional (e.g. GP, school nurse, health visitor, therapist)	<input type="checkbox"/> Pastoral organisation (e.g. religious, spiritual, cultural)
<input type="checkbox"/> PA or childminder	<input type="checkbox"/> Nobody
<input type="checkbox"/> Private professional (e.g. private therapist, childcare provider)	Other (please specify): <input type="text"/>
	<input type="text"/>

22. When was the last time you took the following time off from caring for your child with a disability/additional needs?

	Never	In the last week	In the last month	In the last 6 months	In the last year	In the last 2 years	In the last 5 years
A day/evening off from caring							
A weekend off from caring							
A week off from caring							

Combining work and caring

23. What is your current employment situation? Please tick all that apply.

- | | |
|--|---|
| <input type="checkbox"/> In full-time paid work | <input type="checkbox"/> Not in paid work for other reasons (e.g. immigration status) |
| <input type="checkbox"/> In part-time paid work | <input type="checkbox"/> Voluntary work |
| <input type="checkbox"/> Looking for paid work | <input type="checkbox"/> Retired |
| <input type="checkbox"/> In education/training | Other (please specify): <input type="text"/> |
| <input type="checkbox"/> Not in paid work because of caring responsibilities | <input type="text"/> |
| <input type="checkbox"/> Not in paid work due to own illness or disability | <input type="text"/> |

24. Has caring affected your ability to work? Please tick all that apply. (We know it can be hard to separate this from your general parenting duties, but please tick only if this is as a result of caring for your child with a disability/additional needs.)

- | | |
|--|--|
| <input type="checkbox"/> Caring does not affect my ability to work (go to question 27) | <input type="checkbox"/> I have taken a less challenging job because of my caring responsibilities |
| <input type="checkbox"/> I have reduced my hours because of my caring responsibilities | <input type="checkbox"/> I have had to give up work because of my caring responsibilities |

25. If you feel that caring has affected your ability to work, please give reasons. Tick all that apply:

- | | |
|---|--|
| <input type="checkbox"/> I couldn't find suitable childcare for my child with a disability/additional needs | <input type="checkbox"/> SEN transport won't drop off/pick up from childcare setting |
| <input type="checkbox"/> I couldn't afford the childcare for my child with a disability/additional needs | <input type="checkbox"/> I have to look after my young person on the days when they are not in college |
| <input type="checkbox"/> I frequently need time off to look after my child because of their medical needs | <input type="checkbox"/> My caring responsibilities take too much time/energy |
| <input type="checkbox"/> I frequently need time off to look after my child when they have unscheduled time off school (e.g. exclusions) | Other (please specify): <input type="text"/> |
| | <input type="text"/> |

26. If your own or your partner's work status has changed as a result of caring for a child with a disability/ additional needs, what financial impact has this had on your family?

- | | | |
|------------------------------------|--------------------------------------|---|
| <input type="checkbox"/> No impact | <input type="checkbox"/> Some impact | <input type="checkbox"/> Significant impact |
|------------------------------------|--------------------------------------|---|

27. Are you accessing any means-tested benefits (excluding child benefit)?

- | | |
|------------------------------|-----------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|------------------------------|-----------------------------|

28. If you are in paid employment, has your employer agreed to flexible working arrangements?

- | | | |
|------------------------------|-----------------------------|-------------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | Comments <input type="text"/> |
| <input type="text"/> | | |

29. If you are working, please tell us what sort of childcare you currently use for your child with a disability/ additional needs:

- | | | |
|---|---|--|
| <input type="checkbox"/> Private nursery | <input type="checkbox"/> Mainstream after-school club | <input type="checkbox"/> Family member |
| <input type="checkbox"/> Children's Centre | <input type="checkbox"/> Specialist after-school club | <input type="checkbox"/> Friend/neighbour |
| <input type="checkbox"/> Childminder | <input type="checkbox"/> Mainstream holiday club | Other (please specify): <input type="text"/> |
| <input type="checkbox"/> Personal assistant | <input type="checkbox"/> Specialist holiday club | <input type="text"/> |

30. Do you feel that this type of childcare is adequate for meeting your child's needs?

- | | |
|---|-----------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| If No, please tell us why: <input type="text"/> | |
| <input type="text"/> | |

Education

31. Please tell us what type of educational provision your child with a disability/additional needs CURRENTLY receives.

- Nursery/children's centre
- Primary school mainstream
- Primary school - special
- Primary school - Integrated Resource
- Secondary school - mainstream
- Secondary school - special
- Secondary school - Integrated Resource
- Unit for permanently excluded pupils (PRU)
- Sheffield College

- University
- Independent specialist provider
- Home and Hospital Service
- Home educated by choice
- Home educated as no other option

Other/comments

32. Do you think this educational provision is adequate for meeting your child's needs?

- Yes
- No
- Don't know

If No, please tell us why:

33. For how many days per week does your child receive this educational provision? (1 day = 6.5 hours)

- Less than one day
- 1 day
- 2 days

- 3 days
- 4 days
- 5 days

34. If your young person doesn't attend school or college full-time, what do they do on the other days?

- Independent study
- I look after them as they are not safe to be left on their own
- A Personal Assistant looks after them
- Work placement
- Part-time employment

- Day care centre for disabled people

Other/comments

35. What level of additional support is your child currently getting at nursery/school/college?

- Has a statement of SEN
- Is being assessed for a statement of SEN
- Statement refused after assessment
- Request for assessment refused
- School Action
- School Action Plus
- Has a Learning Difficulty Assessment (Section 139a)

- Not getting any additional support

- Don't know

If statutory assessment or statement refused, what were the reasons given?

36. Have you ever been discouraged from applying for a statement of SEN?

- Yes
- No

If yes, who discouraged you and what were the reasons given?

37. If your child with a disability/additional needs is currently using any of the educational support services listed below, please rate the quality and quantity of provision.

Quality	Excellent	Good	Fair	Poor	Very poor
Educational Psychology					
Autism Service					
Visually Impaired Service					
Hearing Impaired Service					
Learning Support Service					
Home and Hospital Service					

Quantity	Too little	About right	Too much
Educational Psychology			
Autism Service			
Visually Impaired Service			
Hearing Impaired Service			
Learning Support Service			
Home and Hospital Service			

38. Are there any education services which your child needs but is not currently getting?

<input type="checkbox"/> Yes	<input type="checkbox"/> No	If yes, please tell us which:

39. What kind of support does your child with a disability/additional needs receive in their education setting? Please tick all that apply.

	Provided and sufficient	Provided, but insufficient	Not provided, but needed	Not provided and not needed	Don't know
Support in the classroom					
Support at lunchtime/breaktime					
Support to access clubs					
Support to access after-school provision					
Support to go on school trips					
Additional pastoral support					
Other/comments:					

40. Has your child with a disability/additional needs experienced any of the following?

Please tick all that apply.

	Never	Rarely	Sometimes	Frequently	Don't know
Bullying from other children					
Bullying from staff					
Social ostracism (e.g. only child in class not invited to a party)					
Temporary exclusion					
Permanent exclusion					
Unlawful exclusion (e.g. child sent home or asked to stay at home because school did not have enough support staff)					
Other/comments:					

41. If your child is over 16: how would you describe the transition to post-16 education?

- Very easy
- Easy
- Difficult
- Very difficult

How could the transition process be improved?

42. Do you have any other comments about education services?

Social Care

43. Does your child currently receive a short break service (e.g. SNIPS, short breaks grant, overnight respite, direct payments)?

- Yes (go to question 45)
- No

44. If you are not currently accessing a short break service, please tell us why:

- Lack of information about these services
- We don't want them
- We don't need them
- We are not eligible
- Too complicated - we tried and gave up
- There were no activities suitable for my child's needs

- There were no activities suitable for my child's age group
- There were no activities my child wanted to do
- The activities were too far away

Other/comments:

45. Please tell us what kind of short break/respite services your child is currently accessing (tick all that apply).

- SNIPS mainstream club - term time
- SNIPS mainstream club - school holidays
- SNIPS specialist club - term time
- SNIPS specialist club - school holidays
- Overnight respite - term time
- Overnight respite - school holidays
- Ryegate House

- Club/activity run by parent support group
- Short breaks grant (one-off, up to £400)
- Direct Payments - up to 5 hours per week
- Direct Payments - more than 5 hours per week

Other (please specify)

46. Which of these statements best describes how you feel about the short breaks/respite package your family receives?

- I am happy with the level of support we receive
- I just about manage with our current package
- I don't think our package is enough to meet our needs
(please give reasons in the boxes on the right)

47. If your child's short breaks/respite were to be reduced in the future, what impact would this have on your family?

- | | |
|--|---|
| <input type="checkbox"/> No impact: it wouldn't make a difference | <input type="checkbox"/> Significant impact: we would struggle to cope |
| <input type="checkbox"/> Mild impact: life would be more difficult but we would manage | <input type="checkbox"/> Devastating impact: high risk that our family might end up in crisis |

48. If your child is over 18: how would you describe the transition to adult social care?

- | | | | |
|------------------------------------|-------------------------------|------------------------------------|---|
| <input type="checkbox"/> Very easy | <input type="checkbox"/> Easy | <input type="checkbox"/> Difficult | <input type="checkbox"/> Very difficult |
|------------------------------------|-------------------------------|------------------------------------|---|

How could the transition process be improved?

<input type="text"/>
<input type="text"/>
<input type="text"/>

49. Do you have any other comments about social care services?

<input type="text"/>
<input type="text"/>
<input type="text"/>
<input type="text"/>

Direct Payments and Personal Budgets

50. Do you currently receive a Direct Payment or Personal Budget?

- | | | | |
|--|---|-----------------------------|--|
| <input type="checkbox"/> Yes, Direct Payment | <input type="checkbox"/> Yes, Personal Budget | <input type="checkbox"/> No | <input type="checkbox"/> No, but would like to |
|--|---|-----------------------------|--|

51. If Yes, how easy did you find it to access and manage your Direct Payment or Personal Budget?

	Very easy	Easy	Difficult	Very difficult
Access				
Manage				
Comments:				

52. What are you using your Direct Payment or Personal Budget for?

- | | |
|---|--|
| <input type="checkbox"/> Personal Assistant | <input type="checkbox"/> Support in education/training |
| <input type="checkbox"/> Leisure activity | <input type="checkbox"/> Equipment |
| <input type="checkbox"/> Overnight respite | Other (please specify) <input type="text"/> |

53. Is the Direct Payment / Personal Budget sufficient to meet your child's needs?

<input type="checkbox"/> Yes	<input type="checkbox"/> No	Comments <input type="text"/>
<input type="text"/>		
<input type="text"/>		
<input type="text"/>		

54. Do you prefer Direct Payments or a Council service?

- | | | |
|--|--|-------------------------------|
| <input type="checkbox"/> Direct Payments | <input type="checkbox"/> Council service | Comments <input type="text"/> |
| <input type="text"/> | | |

Health services

55. If your child is currently using any of the health services listed below, please rate the quality and quantity of provision.

Quality of provision	Excellent	Good	Fair	Poor	Very poor
Speech and Language Therapy					
Physiotherapy					
Occupational Therapy					
CAMHS (Child and Adolescent Mental Health Service)					
GP (family doctor)					
Health Visitor					
Dentist (NHS)					
Dentist (private)					
Dentist (community)					
Hospital (Ryegate)					
Hospital (A&E)					
Hospital (Outpatients)					
Hospital (Inpatients)					
Continence service (nappies etc.)					
School nurse					

Quantity of provision	Too little	About right	Too much
Speech and Language Therapy			
Physiotherapy			
Occupational Therapy			
CAMHS (Child and Adolescent Mental Health Service)			
GP (family doctor)			
Health Visitor			
Dentist (NHS)			
Dentist (private)			
Dentist (community)			
Hospital (Ryegate)			
Hospital (A&E)			
Hospital (Outpatients)			
Hospital (Inpatients)			
Continenence service (nappies etc.)			
School nurse			

Other comments

56. Are there any health services your child needs but is not currently getting?

Yes

No

If yes, please tell us which:

[Large empty box for writing]

57. Are you currently paying privately for any health services for your child?

Yes

No

If yes, please tell us which:

[Large empty box for writing]

58. What makes it difficult for you and/or your child to access health services?

- | | |
|---|---|
| <input type="checkbox"/> Lack of information about services | <input type="checkbox"/> Staff don't understand child's needs |
| <input type="checkbox"/> Professionals not taking my concerns seriously | <input type="checkbox"/> English is not my first language |
| <input type="checkbox"/> Unclear referral routes | <input type="checkbox"/> My own health/disability |
| <input type="checkbox"/> Child finds waiting very difficult | Other (please specify) [Large empty box for writing] |
| <input type="checkbox"/> Waiting area too busy | [Large empty box for writing] |
| <input type="checkbox"/> Transport | [Large empty box for writing] |

59. If your child has made the transition to adult health services: how would you describe the transition process?

- | | | | |
|---|-------------------------------|------------------------------------|---|
| <input type="checkbox"/> Very easy | <input type="checkbox"/> Easy | <input type="checkbox"/> Difficult | <input type="checkbox"/> Very difficult |
| How could the transition process be improved? [Large empty box for writing] | | | |
| [Large empty box for writing] | | | |
| [Large empty box for writing] | | | |
| [Large empty box for writing] | | | |

60. Do you have any other comments about health services?

[Large empty box for writing]
[Large empty box for writing]
[Large empty box for writing]
[Large empty box for writing]

General

61. Is there any training that would help you cope with the demands of caring for your child?

- | | |
|---|--|
| <input type="checkbox"/> Understanding disability benefits | <input type="checkbox"/> Lifting and handling |
| <input type="checkbox"/> Understanding my rights as a carer | <input type="checkbox"/> Supporting speech & language development |
| <input type="checkbox"/> Understanding the SEN system | <input type="checkbox"/> Helping my child with sleep |
| <input type="checkbox"/> Assertiveness/communication training | <input type="checkbox"/> Helping my child with toilet training |
| <input type="checkbox"/> Coping with stress | <input type="checkbox"/> Helping my child with eating/feeding issues |
| <input type="checkbox"/> Preparing for transition | <input type="checkbox"/> Helping my child be safe in traffic |
| <input type="checkbox"/> Understanding my child's condition | Other (please specify) [Large empty box for writing] |
| <input type="checkbox"/> Managing challenging behaviour | [Large empty box for writing] |

62. Have you ever had to make a complaint about a service?

	Informally	Formally	Sought legal advice	Taken legal action
Education				
Health				
Social Care				
Comments:				

63. Thinking about your child with a disability/additional needs, what three things would make life easier/better for your family? If you can only think of one or two, that's fine. If you can think of more than three, please choose the three most important ones.

1

2

3

64. Can you think of any examples of good practice we could share?

65. In relation to your child with a disability/additional needs, who or what do you value most?

66. Is there anything you wish you'd known earlier?

67. If you'd like us to contact you about any issues you've raised in your response, including training opportunities for parent carers, please write your contact details into the box below. We will not share your details with anyone else.

Name

Address

Email

! Reminder: to take part in our prize draw, please enclose a separate sheet of paper with your name and contact details. Thank you for taking part in this survey!