




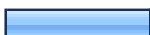



























1. How old is your disabled child?

		Response Percent	Response Count
0-3 years		3.7%	5
3-5 years		8.1%	11
5-8 years		13.2%	18
8-11 years		25.7%	35
11-14 years		26.5%	36
14-19 years		22.8%	31
answered question			136
skipped question			3

2. How would you describe your child's MAIN disability?

		Response Percent	Response Count
Autistic Spectrum Disorder		41.2%	56
Behavioural Emotional or Social Difficulties		8.8%	12
Hearing Impairment		2.2%	3
Visual Impairment		1.5%	2
Multi-Sensory Impairment		0.7%	1
Moderate Learning Difficulty		7.4%	10
Severe Learning Difficulty		15.4%	21
Profound and Multiple Learning Difficulty		5.9%	8
Speech, Language and Communication Needs		2.2%	3
Physical Disability		5.1%	7
Medical Needs or Long-term Illness		6.6%	9
Mental Health Difficulties		2.9%	4
Other / additional needs (please give a short description):			92
answered question			136
skipped question			3












3. ALL main disabilities

		Response Percent	Response Count
Not specified		2.2%	3
Autistic Spectrum Disorder		46.0%	64
Severe Learning Difficulty		19.4%	27
Behavioural Emotional or Social Difficulties		24.5%	34
Profound and Multiple Learning Difficulty		5.8%	8
Hearing Impairment		3.6%	5
Speech, Language and Communication Needs		20.1%	28
Visual Impairment		7.9%	11
Physical Disability		10.1%	14
Multi-Sensory Impairment		3.6%	5
Medical Needs or Long-term Illness		14.4%	20
Moderate Learning Difficulty		19.4%	27
Mental Health Difficulties		7.9%	11
Dyslexia		0.0%	0
answered question			139
skipped question			0

4. ALL disabilities including other

		Response Percent	Response Count
Not specified		2.2%	3
Autistic Spectrum Disorder		48.9%	68
Severe Learning Difficulty		21.6%	30
Behavioural Emotional or Social Difficulties		33.8%	47
Profound and Multiple Learning Difficulty		5.8%	8
Hearing Impairment		5.0%	7
Speech, Language and Communication Needs		28.1%	39
Visual Impairment		7.9%	11
Physical Disability		19.4%	27
Multi-Sensory Impairment		4.3%	6
Medical Needs or Long-term Illness		22.3%	31
Moderate Learning Difficulty		23.0%	32
Mental Health Difficulties		10.1%	14
Dyslexia		6.5%	9
answered question			139
skipped question			0



5. Please state your ethnic group:

		Response Percent	Response Count
White British		82.4%	112
White Irish		0.0%	0
Any other white background		0.7%	1
Traveller of Irish heritage		0.0%	0
Gypsy		0.0%	0
White and black Caribbean		1.5%	2
White and black African		0.7%	1
White and Asian		2.2%	3
Any other mixed background		1.5%	2
Indian		0.0%	0
Pakistani		6.6%	9
Bangladeshi		0.0%	0
Any other Asian background		0.0%	0
Caribbean		0.0%	0
African		1.5%	2
Any other black background		0.7%	1
Chinese		0.0%	0
Yemeni		0.7%	1
Any other ethnic group		0.0%	0
Prefer not to say		1.5%	2
answered question			136
skipped question			3

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

	Response Count
	126
answered question	126
skipped question	13

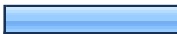






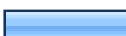

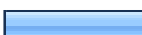

7. Have you ever sought information, advice or support in relation to caring for your disabled child, but couldn't find a service that offered what you were looking for?

		Response Percent	Response Count
Yes		43.0%	55
No		57.0%	73

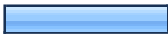


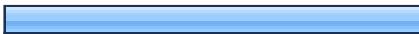












If you answered "Yes", could you tell us what you needed help with? 55

answered question	128
skipped question	11

8. Please tell us which people or organisations you have asked for information, advice or support in relation to your disabled child. Please tick all that apply. (To find out more about the organisations listed, just click on the blue text.)

		Response Percent	Response Count
Social worker		27.7%	36
Health professional		69.2%	90
School staff		67.7%	88
Local parent support group		32.3%	42
Sheffield Parent Partnership Service		43.1%	56
Sheffield Parents as Carers Advice Service		13.1%	17
Sheffield Parent Carer Forum		32.3%	42
Sheffield Carers Centre		19.2%	25
SIGN		53.8%	70
National charity (e.g. Contact a Family, IPSEA)		21.5%	28
Citizen's Advice Bureau		17.7%	23
	Other/comments:		30
answered question			130
skipped question			9

9. Please tell us IN WHICH AREAS you currently need, or have needed, information, advice and support in relation to your disabled child. This includes help understanding the "system" and the options available, and help accessing the services listed. Please tick all that apply.

		Response Percent	Response Count
Legal advice (e.g. advice on your child's rights, tribunal appeals)		25.8%	33
Financial advice (e.g. debt advice)		10.2%	13
Employment advice (e.g. carers' rights in the workplace)		18.0%	23
Benefit applications, renewals and appeals (e.g. DLA/PIP, Carers Allowance, Blue Badge)		67.2%	86
Child health services (e.g. CAMHS, Ryegate, Speech and Language Therapy)		62.5%	80
Social Care services (e.g. Social Worker Assessments, Direct Payments, Respite)		32.8%	42
Support at school or college for my disabled child		61.7%	79
Support with managing my child's behaviour		43.0%	55
Transition to adult services		20.3%	26
Home-to-school transport		31.3%	40
Lifting and handling		7.0%	9
Home adaptations		14.8%	19
Equipment (e.g. mobility aids, communication aids, beds, harnesses, etc.)		21.1%	27
Childcare for my disabled child		20.3%	26
Leisure services for my disabled child		48.4%	62
Support for the brothers and sisters of my disabled child		28.1%	36

Information about specific disabilities		22.7%	29
		Other/comments:	18
		answered question	128
		skipped question	11

10. We want to know HOW parent carers would prefer to receive information, advice and support. Please tell us how important you think it is that a service for parent carers provides the activities listed below:

	Very important	Quite important	Slightly important	Not at all important	Rating Average	Rating Count
Face-to-face appointments	53.2% (66)	33.9% (42)	8.9% (11)	4.0% (5)	2.36	124
Home visits	41.8% (51)	28.7% (35)	24.6% (30)	4.9% (6)	2.07	122
Telephone helpline	52.1% (61)	29.9% (35)	14.5% (17)	3.4% (4)	2.31	117
SMS text messaging service	17.2% (20)	30.2% (35)	37.9% (44)	14.7% (17)	1.50	116
Printed information (e.g. leaflets)	53.3% (64)	33.3% (40)	11.7% (14)	1.7% (2)	2.38	120
Information on a website	59.2% (71)	25.8% (31)	12.5% (15)	2.5% (3)	2.42	120
Social media (e.g. Facebook, Twitter)	16.7% (19)	23.7% (27)	28.9% (33)	30.7% (35)	1.26	114
Support to prepare for assessments and meetings	57.5% (69)	29.2% (35)	10.0% (12)	3.3% (4)	2.41	120
Support at assessments and meetings	52.5% (63)	30.8% (37)	13.3% (16)	3.3% (4)	2.33	120
Support to understand forms, letters and reports	54.2% (64)	27.1% (32)	10.2% (12)	8.5% (10)	2.27	118
Support to complete forms and write letters and reports	53.7% (65)	31.4% (38)	7.4% (9)	7.4% (9)	2.31	121
Support to lodge appeals and prepare for hearings	61.9% (73)	22.9% (27)	10.2% (12)	5.1% (6)	2.42	118
Advocacy (someone speaking or writing on my behalf in relation to a specific issue)	45.1% (51)	29.2% (33)	15.9% (18)	9.7% (11)	2.10	113





Drop-in sessions/coffee mornings for parent carers	27.5% (33)	41.7% (50)	25.0% (30)	5.8% (7)	1.91	120
Emotional support to help me in my caring role	48.8% (59)	33.9% (41)	12.4% (15)	5.0% (6)	2.26	121
Health and wellbeing activities for parent carers	46.6% (55)	31.4% (37)	16.1% (19)	5.9% (7)	2.19	118
Training for parent carers (e.g. assertiveness training, understanding benefit reform)	54.5% (67)	29.3% (36)	8.9% (11)	7.3% (9)	2.31	123

Other/comments: 9

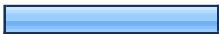
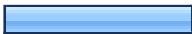





answered question 128

skipped question 11

11. How important is it for you to be able to get all your information, advice and support in relation to caring for your disabled child from a single source?

		Response Percent	Response Count
Very important		69.8%	90
Quite important		21.7%	28
Slightly important		3.9%	5
Not at all important		4.7%	6
		answered question	129
		skipped question	10

12. We want to know what other challenges parents of disabled children face, which might make it more difficult for them to access a support service. Please tick all that apply:

		Response Percent	Response Count
I have more than one disabled child		34.3%	23
I also care for an adult (e.g. disabled partner, elderly parent, adult son/daughter with a disability)		29.9%	20
I have a disability or long-term illness myself		35.8%	24
My English is not very good		1.5%	1
I have difficulty accessing the internet		16.4%	11
I have difficulty accessing a telephone		9.0%	6
I have difficulty accessing transport		22.4%	15
	Other/comments:		32
	answered question		67
	skipped question		72

13. Have we missed anything? Please use this text box for any additional comments about the provision of information, advice and support for parents of disabled children.

	Response Count
	28
answered question	28
skipped question	111

Page 2, Q2. How would you describe your child's MAIN disability?

1	Also listed as main: Physical Disability Other: Ehler's Danlos Syndrome - coordination and gross/fine motor skill delay	May 27, 2013 11:06 AM
2	Illness (viral encephalitis)	May 27, 2013 11:05 AM
3	Also listed as main: BESD, Mental Health Difficulties Other: ADHD	May 27, 2013 11:04 AM
4	Also listed as main: HI, SLCN	May 27, 2013 11:04 AM
5	Also listed as main: BESD, MLD	May 27, 2013 11:03 AM
6	Also listed as main: BESD Other: also being assessed for Dyspraxia	May 27, 2013 11:02 AM
7	Also listed as main: BESD and MLD	May 27, 2013 11:02 AM
8	Anxiety plus mental health difficulties as a result of anxiety and failed school interventions/placement	May 27, 2013 11:01 AM
9	Also listed as main: BESD, S&LC Other: need help communicating, social skills and confidence	May 27, 2013 11:01 AM
10	Also listed as main: BESD, MLD	May 27, 2013 11:00 AM
11	Also ticked as main: MLD Other: Epilepsy	May 27, 2013 11:00 AM
12	Also ticked as main: MLD	May 27, 2013 10:59 AM
13	Also listed as main: S&L, medical needs	May 27, 2013 10:59 AM
14	Also ticked as main: BESD Other: OCD, Dyslexia, dyspraxia	May 27, 2013 10:58 AM
15	Also listed as main: SLD, BESD, Visual impairment, Medical needs	May 27, 2013 10:58 AM
16	Other: communication; moderate learning difficulties; behavioural difficulties	May 27, 2013 10:57 AM
17	Language needs BSL and speech therapy	May 27, 2013 10:57 AM
18	Also listed as main:Speech & Language	May 27, 2013 10:56 AM
19	Also listed as main: BESD, SLD, Medical needs Other: Cerebral Palsy	May 27, 2013 10:56 AM
20	Also ticked as main: BESD, Hearing, Visual, Speech & language, medical Other Down Syndrome	May 27, 2013 10:55 AM
21	Also ticked as main: Moderate Learning Difficulty Other: ADHD ASD? Dyslexia	May 27, 2013 10:55 AM
22	Other: emotional difficulties	May 27, 2013 10:54 AM
23	Also listed as main: Severe Learning Difficulty	May 27, 2013 10:54 AM
24	Full time wheelchair user, non verbal, epilepsy, profound learning disability	May 27, 2013 10:53 AM
25	ADHD with autistic traits	May 27, 2013 10:51 AM
26	Dyspraxia Learning difficulties	May 27, 2013 10:49 AM
27	Cerebral Palsy and Hydrocephalus	May 27, 2013 10:48 AM

Page 2, Q2. How would you describe your child's MAIN disability?

28	Also listed as main: SLCN Other: Severe Epilepsy	May 27, 2013 10:48 AM
29	Also listed as main: ASD, SLCN	May 27, 2013 10:47 AM
30	Also listed as main: ASD, BESD, SLCN	May 27, 2013 10:47 AM
31	Also listed as main: ASD, SLCN, Medical needs or long-term illness, mental health difficulties (severe anxiety / aggression at times)	May 27, 2013 10:46 AM
32	Also listed as main: MLD, SLCN Other: Hydrocephalus	May 27, 2013 10:45 AM
33	Also listed as main: VI, MLD, SLCN, Physical disability	May 27, 2013 10:45 AM
34	Also listed as main: Medical Needs or Long-Term Illness Other: Possible dyslexia, problem with motor skills	May 27, 2013 10:44 AM
35	Also listed as main: ASD, SLCN	May 27, 2013 10:43 AM
36	PDA	May 27, 2013 10:42 AM
37	Also listed as main: visual impairment, physical disability (hydrocephalus)	May 27, 2013 10:42 AM
38	Medical needs and long-term illness, Speech Language and Communication Needs	May 27, 2013 10:41 AM
39	Also listed as main: BESD Listed as Other: Attachment Disorder	May 27, 2013 10:40 AM
40	ADHD	May 27, 2013 10:39 AM
41	Also listed as main: autistic spectrum disorder, multi-sensory impairment, moderate learning difficulty, mental health difficulties Comment: They have ASD & ADHD, as well as multi-sensory difficulties as well as social and communication difficulties and this impacts with behavioural issues also.	May 27, 2013 10:37 AM
42	Also listed as main: multi-sensory impairment	May 27, 2013 10:36 AM
43	Attention Difficulties: finds it hard to concentrate for long, switches quickly to other things. Verbal memory difficulties: forgets easily what's asked of her so needs instructions many times repeated. Dyslexia	May 27, 2013 10:35 AM
44	Dyslexia	May 27, 2013 10:34 AM
45	Severe processing disorder affecting ability to understand verbal and written information and expression	May 27, 2013 10:34 AM
46	Also listed as main: multi-sensory impairment, severe learning difficulty, speech language and communication needs, physical disability, medical needs or long-term illness Comment: A. does not sit up, walk or talk. She has weak muscles. She has epilepsy and is fed through a NG tube.	May 27, 2013 10:32 AM
47	Also listed as main: Moderate Learning Difficulty, Speech Language and Communication Needs, Medical Needs or Long-Term Illness (Short Bowel Syndrome)	May 27, 2013 10:29 AM
48	Dyslexia - this counts! can destroy self esteem Dyspraxia	May 27, 2013 10:28 AM
49	Also listed as main: Down Syndrome, Visual Impairment, Speech, Language and Communication Needs	May 27, 2013 10:28 AM

Page 2, Q2. How would you describe your child's MAIN disability?

50	plus mobility	May 27, 2013 10:27 AM
51	Downs Syndrome	May 27, 2013 10:23 AM
52	Also listed as main: Behavioural Emotional or Social Difficulties, Moderate Learning Difficulty, Visual Impairment	May 27, 2013 10:22 AM
53	Also listed as main: Moderate Learning Difficulty, Medical Needs or Long-Term Illness, Mental Health Difficulties Other: ADHD	May 27, 2013 10:21 AM
54	Also listed as main for two children: Autistic Spectrum Disorder (both), Behavioural Emotional or Social Difficulties (both), Visual Impairment (one), Multi-Sensory Impairment (both but different), Moderate Learning Difficulty (one), Severe Learning Difficulty (one), Speech Language and Communication Needs (one), Physical Disability (both mildly), Medical Needs or Long-term Illness (one with asthma), Mental Health Difficulties (both under CAMHS) Other: I have 2 children with very different areas of need. They clash a lot of the time especially with sensory issues.	May 27, 2013 10:21 AM
55	Also listed as main: Behavioural Emotional or Social Difficulties, Moderate Learning Difficulty, Speech Language and Communication Needs	May 27, 2013 10:19 AM
56	Also listed as main: Autistic Spectrum Disorder, Behavioural Emotional or Social Difficulties, Mental Health Difficulties Other: No self confidence, and would rather be at home on his own than with others	May 27, 2013 10:19 AM
57	Also listed as main: Behavioural Emotional or Social Difficulties, Hearing Impairment, Moderate Learning Difficulty, Speech Language and Communication Needs	May 27, 2013 10:18 AM
58	Also listed as main: Moderate Learning Difficulty, Speech Language and Communication Needs	May 27, 2013 10:18 AM
59	Also listed as main: Behavioural Emotional or Social Difficulties	May 27, 2013 10:17 AM
60	Also listed as main: Moderate Learning Difficulty, Speech Language and Communication Needs	May 27, 2013 10:17 AM
61	Also listed as main: Behavioural Emotional or Social Difficulties Other: ADHD	May 27, 2013 10:17 AM
62	Also listed as main: Behavioural Emotional or Social Difficulties, Severe Learning Difficulty, Speech Language and Communication Needs, Physical Disability	May 27, 2013 10:16 AM
63	Also listed as main: Behavioural Emotional or Social Difficulties, Speech Language and Communication Needs, Mental Health Difficulties	May 27, 2013 10:16 AM
64	Also listed as main: Speech Language and Communication Needs, Medical Needs or Long-Term Illness Other: Cerebral Palsy, Seizures	May 27, 2013 10:15 AM
65	Also listed as main: Autistic Spectrum Disorder, Behavioural Emotional or Social Difficulties, Visual Impairment, Speech Language and Communication Needs, Physical Disability	May 27, 2013 10:15 AM
66	All listed as main: Visual Impairment, Speech Language and Communication Needs, Physical Disability, Medical Needs or Long-Term Illness	May 27, 2013 10:14 AM
67	Dyslexia	May 27, 2013 10:11 AM

Page 2, Q2. How would you describe your child's MAIN disability?

68	Separation Anxiety,Phobias,Post Traumatic Stress Disorder, Aspergers	May 27, 2013 10:10 AM
69	ADHD Asthma	May 27, 2013 10:09 AM
70	Autistic Spectrum Disorder Moderate Learning Difficulty	May 27, 2013 10:08 AM
71	Behavioural Emotional/Social Difficulties Hearing Impairment Visual Impairment Multi-Sensory Impairment Severe Learning Difficulty Speech Language and Communication Needs	May 27, 2013 10:08 AM
72	Autistic Spectrum Disorder ADHD Dyspraxia	May 27, 2013 10:07 AM
73	no movement in any limbs	May 27, 2013 10:06 AM
74	Speech and Language	May 27, 2013 10:06 AM
75	speach n language,dylexia	May 27, 2013 10:05 AM
76	Severe learning disability	May 27, 2013 10:05 AM
77	Has Leukaemia,on treatment,additional speech and social needs	May 27, 2013 10:04 AM
78	Deaf, challenging behaviour	May 27, 2013 10:03 AM
79	Learning difficulties	May 27, 2013 10:03 AM
80	Down syndrome, speech difficulty, hypotonia, mild deafness	May 27, 2013 10:03 AM
81	Severe physical disability	May 27, 2013 10:02 AM
82	behaviour problems	May 27, 2013 10:01 AM
83	ASD, non-verbal, epilepsy, balance and coordination problems	May 27, 2013 10:01 AM
84	moderate learning difficulties	May 27, 2013 10:00 AM
85	ADHD	May 27, 2013 10:00 AM
86	Short bowel syndrome due to bowel surgery	May 27, 2013 9:59 AM
87	also dyspraxia, sensory issues and PDA	May 27, 2013 9:58 AM
88	ADHD Dyslexia ODD	May 24, 2013 12:35 PM
89	ADHD DYSLEXIA	May 24, 2013 12:34 PM
90	Global development delay, non walker, non talker, epilepsy	May 24, 2013 12:30 PM
91	also speech and language problems	May 24, 2013 12:29 PM
92	diabetes 1 - insulin dependent	May 24, 2013 12:26 PM

Page 2, Q6. Please state the first part of your postcode (e.g. S35):

1	S5	May 27, 2013 11:06 AM
2	S2	May 27, 2013 11:06 AM
3	S20	May 27, 2013 11:05 AM
4	s10	May 27, 2013 11:04 AM
5	S2	May 27, 2013 11:03 AM
6	s8	May 27, 2013 11:03 AM
7	s5	May 27, 2013 11:02 AM
8	s20	May 27, 2013 11:02 AM
9	S12	May 27, 2013 11:02 AM
10	s10	May 27, 2013 11:01 AM
11	S12	May 27, 2013 11:01 AM
12	S9	May 27, 2013 11:00 AM
13	S8	May 27, 2013 11:00 AM
14	s7	May 27, 2013 11:00 AM
15	s5	May 27, 2013 10:59 AM
16	S2	May 27, 2013 10:59 AM
17	S11	May 27, 2013 10:58 AM
18	S17	May 27, 2013 10:58 AM
19	S11	May 27, 2013 10:57 AM
20	s20	May 27, 2013 10:57 AM
21	S8	May 27, 2013 10:56 AM
22	S7	May 27, 2013 10:56 AM
23	s5	May 27, 2013 10:55 AM
24	s8	May 27, 2013 10:55 AM
25	s17	May 27, 2013 10:54 AM
26	S9	May 27, 2013 10:54 AM
27	s35	May 27, 2013 10:53 AM
28	S12	May 27, 2013 10:51 AM
29	S10	May 27, 2013 10:49 AM
30	S12 4WX	May 27, 2013 10:48 AM

Page 2, Q6. Please state the first part of your postcode (e.g. S35):

31	S35	May 27, 2013 10:48 AM
32	S20	May 27, 2013 10:47 AM
33	S5	May 27, 2013 10:47 AM
34	S20	May 27, 2013 10:46 AM
35	S12	May 27, 2013 10:45 AM
36	S2	May 27, 2013 10:44 AM
37	S10	May 27, 2013 10:43 AM
38	S2	May 27, 2013 10:42 AM
39	S10	May 27, 2013 10:42 AM
40	S8	May 27, 2013 10:42 AM
41	S11	May 27, 2013 10:41 AM
42	S8	May 27, 2013 10:40 AM
43	s5	May 27, 2013 10:39 AM
44	S13	May 27, 2013 10:39 AM
45	S6	May 27, 2013 10:37 AM
46	S13	May 27, 2013 10:36 AM
47	S5	May 27, 2013 10:35 AM
48	S6	May 27, 2013 10:35 AM
49	S13	May 27, 2013 10:34 AM
50	S8	May 27, 2013 10:34 AM
51	S11	May 27, 2013 10:32 AM
52	S8	May 27, 2013 10:31 AM
53	S17	May 27, 2013 10:29 AM
54	S10	May 27, 2013 10:28 AM
55	S8	May 27, 2013 10:28 AM
56	S35	May 27, 2013 10:28 AM
57	s17	May 27, 2013 10:27 AM
58	s13	May 27, 2013 10:27 AM
59	S20	May 27, 2013 10:27 AM
60	s12	May 27, 2013 10:26 AM

Page 2, Q6. Please state the first part of your postcode (e.g. S35):

61	S8	May 27, 2013 10:23 AM
62	S20	May 27, 2013 10:22 AM
63	S20	May 27, 2013 10:21 AM
64	S10	May 27, 2013 10:21 AM
65	S6	May 27, 2013 10:19 AM
66	S8	May 27, 2013 10:18 AM
67	S11	May 27, 2013 10:18 AM
68	S13	May 27, 2013 10:17 AM
69	S35	May 27, 2013 10:17 AM
70	S12	May 27, 2013 10:17 AM
71	S18	May 27, 2013 10:16 AM
72	S5	May 27, 2013 10:15 AM
73	S6	May 27, 2013 10:15 AM
74	S2	May 27, 2013 10:14 AM
75	S17	May 27, 2013 10:14 AM
76	s35	May 27, 2013 10:13 AM
77	S8	May 27, 2013 10:13 AM
78	S13	May 27, 2013 10:13 AM
79	S6	May 27, 2013 10:13 AM
80	S8	May 27, 2013 10:12 AM
81	S7	May 27, 2013 10:12 AM
82	S20	May 27, 2013 10:12 AM
83	S20	May 27, 2013 10:11 AM
84	S14	May 27, 2013 10:11 AM
85	S11	May 27, 2013 10:11 AM
86	S9	May 27, 2013 10:10 AM
87	S5	May 27, 2013 10:09 AM
88	S12	May 27, 2013 10:09 AM
89	S8	May 27, 2013 10:08 AM
90	S5	May 27, 2013 10:08 AM

Page 2, Q6. Please state the first part of your postcode (e.g. S35):

91	S8	May 27, 2013 10:07 AM
92	S13	May 27, 2013 10:07 AM
93	S9	May 27, 2013 10:06 AM
94	s5	May 27, 2013 10:06 AM
95	S20	May 27, 2013 10:06 AM
96	s20	May 27, 2013 10:05 AM
97	S11	May 27, 2013 10:05 AM
98	S35	May 27, 2013 10:05 AM
99	S7	May 27, 2013 10:04 AM
100	s8	May 27, 2013 10:04 AM
101	s6	May 27, 2013 10:03 AM
102	S17	May 27, 2013 10:03 AM
103	s10	May 27, 2013 10:03 AM
104	S7	May 27, 2013 10:02 AM
105	S6	May 27, 2013 10:02 AM
106	s35	May 27, 2013 10:01 AM
107	s10	May 27, 2013 10:01 AM
108	S7	May 27, 2013 10:01 AM
109	S8	May 27, 2013 10:00 AM
110	S2	May 27, 2013 10:00 AM
111	S12	May 27, 2013 9:59 AM
112	S9	May 27, 2013 9:59 AM
113	S5	May 27, 2013 9:59 AM
114	S5	May 27, 2013 9:58 AM
115	S5	May 27, 2013 9:58 AM
116	s6	May 27, 2013 9:57 AM
117	S10	May 24, 2013 12:35 PM
118	s10	May 24, 2013 12:34 PM
119	S35	May 24, 2013 12:30 PM
120	S6	May 24, 2013 12:29 PM

Page 2, Q6. Please state the first part of your postcode (e.g. S35):

121	S26	May 24, 2013 12:29 PM
122	S32	May 24, 2013 12:28 PM
123	S4	May 24, 2013 12:28 PM
124	S6	May 24, 2013 12:28 PM
125	s17	May 24, 2013 12:27 PM
126	s8	May 24, 2013 12:26 PM

Page 3, Q7. Have you ever sought information, advice or support in relation to caring for your disabled child, but couldn't find a service that offered what you were looking for?

1	Support in school holidays, my child is 15 years old and to get support at his age is very difficult (impossible).	May 27, 2013 11:04 AM
2	Applying for direct payments, Speech and Language	May 27, 2013 11:04 AM
3	A service which offered a "magic wand" to guide you through all the obstacles you encounter whilst trying to get a child with ASD to fit into a "normal" education system. Knowledge and support has been minimal, struggling day to day leaves little time to search for answers. I've generally done lots of reading and investigating in the early hours; searching for answers/ideas as to how to help my daughter.	May 27, 2013 11:01 AM
4	Respite care, educational workshops, activities based on learning	May 27, 2013 11:00 AM
5	I have realised that my child need specialist help and he is waiting for an assessment at the childrens hospital	May 27, 2013 10:59 AM
6	Initial diagnosis - not being believed by doctors School - mainstream, statement, secondary school Sleep - support/ medication Social Support ie Direct Payments Extra curricular activities and provision providers	May 27, 2013 10:59 AM
7	Respite	May 27, 2013 10:58 AM
8	Information on sleep and toileting. Interventions/treatment Initial diagnosis - more information on how the condition affects my child	May 27, 2013 10:57 AM
9	Transport, education. Impartial and honest advice	May 27, 2013 10:57 AM
10	Respite services	May 27, 2013 10:56 AM
11	Advice on: statementing, SNIPS, medication, learning difficulties, psychology	May 27, 2013 10:55 AM
12	So far I have found it extremely difficult to find appropriate help and the right services for my child or support for myself so that I can help him. I have found that each agency is passing me to the other. No one wants to take ownership of this issue. This has caused a huge amount of distress for my entire family.	May 27, 2013 10:54 AM
13	direct payments / social worker / housing adaptations / after school, extra curricular activities	May 27, 2013 10:53 AM
14	Respite care, breaks, funding	May 27, 2013 10:51 AM
15	Asked for social worker to help get support for Direct Payments but no outcome - passed from pillar to post - no one seems interested.	May 27, 2013 10:51 AM
16	a hydrocephalus group	May 27, 2013 10:48 AM
17	Sporting activities / support for less able disabled. Support for disabled carer. For years requested a carer's assessment, never got a proper assessment, told to pay for help (can't afford it) or to apply for DLA in my own right. Currently awaiting/dreading an ESA tribunal, need help with representation - any ideas? (telephone number supplied)	May 27, 2013 10:46 AM
18	Contacted ASBAH (now SHINE) to fill in DLA forms with me	May 27, 2013 10:45 AM
19	Childcare for siblings, one with and one without a disability. Babysitting	May 27, 2013 10:42 AM

Page 3, Q7. Have you ever sought information, advice or support in relation to caring for your disabled child, but couldn't find a service that offered what you were looking for?

	(occasional for respite)	
20	What is my daughter entitled to when she leaves school (college)	May 27, 2013 10:42 AM
21	CHILDCARE - after school and holiday for secondary age. AND respite care	May 27, 2013 10:41 AM
22	School and outside school activities. I've struggled constantly with school issues during his secondary school life and didn't get any positive help from them. Find it difficult to find local out of school hours activities for him, also as he's better in small groups which most places don't cater for.	May 27, 2013 10:37 AM
23	Activity centres near where we live. There is very few in the S6 area and have to travel a lot which puts me off especially in winter	May 27, 2013 10:35 AM
24	1:1 swimming lessons	May 27, 2013 10:34 AM
25	Home tutor for my son as an addition to school to help on a one-to-one basis	May 27, 2013 10:31 AM
26	Signposting at school - how to get acces to diagnosis/assessment that was helpful and not too stressful for our child. No information when we were really worried in infant school.	May 27, 2013 10:28 AM
27	Getting help in nursery. Filling in reasons for applying to a certain school.	May 27, 2013 10:28 AM
28	I required help with an appeal against DLA but unfortunately never found the help so didn't go ahead with my appeal.	May 27, 2013 10:28 AM
29	help into getting my daughter into a specific school to help her needs	May 27, 2013 10:27 AM
30	sheffield city housing	May 27, 2013 10:27 AM
31	I've found help now but it's very difficult to find it. Having children in special school changes everything and everything is handed to me on a plate now. The system is not fair, e.g. Speech and Language Therapy - we had an assessment in school about once a term - now we have 2 Speech and Language Therapists helping us and they even come to our house. They are in school twice a week.	May 27, 2013 10:21 AM
32	Access to advice and groups	May 27, 2013 10:16 AM
33	A long time ago - internet etc a lot better now! Very frustrating finding anything out - things have improved a lot more. Changing social workers - be nice to have one longer.	May 27, 2013 10:15 AM
34	Early years inclusion service excellent service especially Jo Kite.	May 27, 2013 10:13 AM
35	Sleeping issue especially as when it happens you need help immediatly.	May 27, 2013 10:12 AM
36	Support and therapy for Post Traumatic Stress Disorder and separation anxiety and behavioural and emotional difficulties at school that they didn't know how to help.	May 27, 2013 10:10 AM
37	Out of school childcare.	May 27, 2013 10:08 AM
38	Respite	May 27, 2013 10:07 AM
39	Transport. Had some real difficulty sorting a basic request with Sheffield City	May 27, 2013 10:06 AM

Page 3, Q7. Have you ever sought information, advice or support in relation to caring for your disabled child, but couldn't find a service that offered what you were looking for?

	Council as a deaf parents despite emailing several times. Martin Green has written to us several times by mail and texted my partner so "communication breakdown" in the "departmental restructure" cuts very little ice with me.	
40	Sleep	May 27, 2013 10:05 AM
41	Childcare in school holidays.	May 27, 2013 10:04 AM
42	Difficult when i had to move due to medical priority.I was trying to find a decorating service which was inexpensive due to not having the money for a trade decorator and also a handyperson to do curtain rails etc.My little boy was ill whilst i was moving which added to the stress.I do not understand why no such schemes exist for carers as they do for older people.I am deeply in debt now due to paying decorators and removals.The house was in such a mess it was impossible to move in with my Son due to the nature of his illness.	May 27, 2013 10:04 AM
43	Respite care for overnight	May 27, 2013 10:03 AM
44	Holiday club close to where we live.	May 27, 2013 10:03 AM
45	Finding social activities for disabled children; help with learning to ride a bike; baby sitters when he was very young.	May 27, 2013 10:03 AM
46	After school child care and holiday care for working parents	May 27, 2013 10:02 AM
47	Adhoc childcare. Someone who can care for my child who really reallt knows about their needs.	May 27, 2013 10:01 AM
48	advice on behaviour management in school understanding direct payments	May 27, 2013 10:01 AM
49	Behavior support Coping strategies Health implications at nursery	May 27, 2013 9:59 AM
50	Help with direct payments, help with finding a social worker, help with being rehoused	May 24, 2013 12:30 PM
51	general support, advice on disipline as nothing works(we do warnings,time out, loss of privialege such as tv/computer game)	May 24, 2013 12:29 PM
52	school place, money	May 24, 2013 12:28 PM
53	ADHD support group	May 24, 2013 12:28 PM
54	support groups	May 24, 2013 12:27 PM
55	help with organising a holiday for the family re cost towards this but we don't meet the criteria or threshold because we both work.	May 24, 2013 12:26 PM

Page 3, Q8. Please tell us which people or organisations you have asked for information, advice or support in relation to your disabled child. Please tick all that apply. (To find out more about the organisations listed, just click on the blue text.)

1	Facebook groups	May 27, 2013 11:06 AM
2	I am always open to support, it's just unfortunate that it's short and sweet, there is no on-going support for me and my son.	May 27, 2013 11:04 AM
3	We are currently under the MAST team Our MAST worker is Dave Hargreaves	May 27, 2013 11:03 AM
4	The best support on a regular basis has been from other parents in a similar position online. CAMHS has been invaluable but waiting times are too long and appointments could be more regular/ more frequent	May 27, 2013 11:01 AM
5	Have tried National Autism Line and also Hope for Autism in Scotland	May 27, 2013 11:01 AM
6	Failed to implement any respite care (overnight)	May 27, 2013 10:58 AM
7	Sheffield Parent Partnership never responded to my calls - I didn't bother after this. School didn't listen to me - had a an attitude - we are the professionals and know best about your child Health professionals - mixed experiences some ver bad some OK SIGNonly seend out leaflets - some were out of date for contact numbers for groups	May 27, 2013 10:57 AM
8	Deaf Advice Service Sheffield	May 27, 2013 10:57 AM
9	SNIPS	May 27, 2013 10:56 AM
10	National Charity:St Vincent	May 27, 2013 10:55 AM
11	I was'nt aware that the other groups exist. This actually highlights how big the problem is, because having seen by CAMHS, Ryegate, MAST, local GP and hospital, I have not been advised about these services to support me.	May 27, 2013 10:54 AM
12	MAST Team	May 27, 2013 10:51 AM
13	Ryegate	May 27, 2013 10:47 AM
14	Plenty information for more able disabled. If your child has SLD and severe autism, life-threatening allergies have nowhere to turn to for support. Harder if you have no family support/"friends" willing to support you. Am getting a bit of support now 18+ - from son's support plan. For my son to go out and be part of the community!!! at last.	May 27, 2013 10:46 AM
15	SHINE	May 27, 2013 10:45 AM
16	Numerous sources can be confusing	May 27, 2013 10:42 AM
17	Didn't find SIGN helped. They TRIED - but by sending a long email of info, and I found it very hard to understand what they were talking about.	May 27, 2013 10:41 AM
18	Parent Partnership are helping us as a family, giving me and my son lots of support. SIGN is also giving help and support.	May 27, 2013 10:39 AM
19	His main health professional has been very helpful with most of my concerns. School has not however. I've got most information and support from Ray of Hope support group. Also I've had some assistance at school meetings from Parent Partnership when they have been able to fit us in due	May 27, 2013 10:37 AM

Page 3, Q8. Please tell us which people or organisations you have asked for information, advice or support in relation to your disabled child. Please tick all that apply. (To find out more about the organisations listed, just click on the blue text.)

	to the demand on their services. Newsletters and information also from Parent Carer Forum and SIGN.	
20	INDEPENDENT Speech and Language Therapist	May 27, 2013 10:34 AM
21	Family Fund for older age pushchair	May 27, 2013 10:29 AM
22	ACCT	May 27, 2013 10:28 AM
23	If I want help with something I stick at it for hours.	May 27, 2013 10:21 AM
24	Some of these may have just been looking on the internet for advice as well as face to face with others.	May 27, 2013 10:19 AM
25	Ray of Hope support group who keep up to date with information (that you supply to them)	May 27, 2013 10:17 AM
26	Sheffield Autistic Society also best source of information has been from other parents	May 27, 2013 10:05 AM
27	I haven't used the Parents as Carers service as they have only recently been established, and the need has not arisen so far.	May 27, 2013 10:03 AM
28	Snips	May 27, 2013 10:02 AM
29	Central Gov depts (DfE, inland Revenue) Local Gov (SEN dept)	May 27, 2013 10:01 AM
30	We had a lovely support worker from the inclusion service who's help for our daughter was invaluable. However I have been informed today that due to SCC funding cuts we have lost her. Don't know how our daughter will cope in nursery now.	May 27, 2013 9:59 AM

Page 3, Q9. Please tell us IN WHICH AREAS you currently need, or have needed, information, advice and support in relation to your disabled child. This includes help understanding the "system" and the options available, and help accessing the services listed. Please tick all that apply.

1	I have received information about music lessons for my son	May 27, 2013 11:03 AM
2	She needs a lot of help and support. She really needs someone to talk to and help her with the changes of her routine in life especially the move from her house in Scotland down to Sheffield, At the moment she can't deal with it all,	May 27, 2013 11:01 AM
3	Expect to need social worker assessment within 2 years. Also with transition to adult services for 2 sons (1 x Austistic Spectrum & 1 lifelong Health Condition (Type 1 Diabetes).	May 27, 2013 11:00 AM
4	From birth to present (he is now 14 years old) i've needed and still need the above and it's up to me bring them together and to provide information or find information etc, extremely exhausting, frustrating and demoralising	May 27, 2013 10:59 AM
5	I feel that there are massive gaps between all these different services - there is a lack of communication and it is extremely frustrating to go through everything all over agsin, everytime you see a new face. On a daily basis I face difficulties but I feel that there is no help out there for me or for by child who finds things hard at school.	May 27, 2013 10:54 AM
6	Parent ticked "Child health services" and underlined "Ryegate"	May 27, 2013 10:52 AM
7	Parent highlighted "Help with managing my child's behaviour"	May 27, 2013 10:51 AM
8	Still waiting for help with lifting and handling!	May 27, 2013 10:48 AM
9	Support with managing child's behaviour: aggression/anxiety from puberty. very important - awaiting help!!! Home-to-school transport: initially refused - re. severe peanut allergy. Epipen training eventually awarded Equipment: communication aids when younger would have been very helpful. My son was refused respite care in social services and private sector due to having a severe peanut/nut allergy - egg allergy, allergic to horses, masked HDM??? Daughter (twin sister) has had to move out and rent a house with a friend (paid for by plan) to give me a break. Transition stage - was total nightmarek - plan kept being refused! EVENTUALLY common sense from Ruth McKinskey / Mencap Gateway (wonderful Dalia and Darren) prevailed. Are you aware residential respite for 18+ year olds in Sheffield is CRAP!!! Places available want to "cherry pick" and have nothing e.g. computers, Xbox, PlayStation or even DVD players in some places.	May 27, 2013 10:46 AM
10	Legal advice and benefit renewal has been sought through my housing association through their benefits advisor.	May 27, 2013 10:44 AM
11	Childcare and leisure services in Sheffield operate on normal behaviour management techniques. Poor behaviour results in child being excluded - this is acceptable according to OFSTED as long as it is stated in the behaviour policy.	May 27, 2013 10:42 AM
12	My son has not been in school for 5 months and I feel 1 hour a day schooling at home is not enough, and things don't seem to be getting? and near to him been placed in a school!! I was told in January he had ADHD, why he is not in school yet is unbelievable.	May 27, 2013 10:39 AM
13	I find there's no small group leisure activities local to me. I've never had help	May 27, 2013 10:37 AM

Page 3, Q9. Please tell us IN WHICH AREAS you currently need, or have needed, information, advice and support in relation to your disabled child. This includes help understanding the "system" and the options available, and help accessing the services listed. Please tick all that apply.

with transport for him, I've done it myself but in Y11 the school have suggested Independent Travel Training now he's leaving. Don't know anything about transition to adult services which will affect him shortly. Find benefit forms very repetitive and time consuming and draining whilst trying to look after two disabled children and their needs also.

14	My child is dyslexic and have sent off for some info from SIGN	May 27, 2013 10:34 AM
15	Help regarding child's statement. Occupational Therapy at Ryegate	May 27, 2013 10:29 AM
16	Somewhere that does small groups for health and fitness sessions as he doesn't like groups of more than 8 to 10 and feels embarrassed in front of more able bodied children.	May 27, 2013 10:19 AM
17	Help understanding the transition from nursery to school.	May 27, 2013 10:13 AM
18	Everything!	May 27, 2013 10:01 AM

Page 3, Q10. We want to know HOW parent carers would prefer to receive information, advice and support. Please tell us how important you think it is that a service for parent carers provides the activities listed below:

1	It is very difficult to attend support groups as i am so busy with my child who is home educated some of the time and who is afraid to be left alone for long periods. Things are improving so maybe one day?	May 27, 2013 11:01 AM
2	Last statement above 'Training for parent carers' - we don't need this but it might be very important to others.	May 27, 2013 11:00 AM
3	I think there is a lack pf interaction and often a lot of services seem like they are a "tick in the box" service.	May 27, 2013 10:54 AM
4	I don't have the time for drop-in sessions / coffee mornings!	May 27, 2013 10:48 AM
5	Transition period - needs drastic improvement and present support is totally inadequate!	May 27, 2013 10:46 AM
6	Often we need to TALK things through. So information on its own in whatever format, is NOT enough.	May 27, 2013 10:41 AM
7	I think services are very important for parents, having two disabled children I struggle to get to meetings etc. as one may be at school the other won't be, so it's very difficult to guarantee that I can get to appointments and meetings. Leafets, texts etc. I can get to look at during a spare second.	May 27, 2013 10:37 AM
8	I think its very important that home visits are carried out then you can access what the problem is.	May 27, 2013 10:07 AM
9	Trying to arrange home-school transport so I could work was impossible. This is a huge problem as I need to work to pay my mortgage and feed us! The policy appears very rigid and it took me a lot of effort to get support from the home-school transport team.	May 27, 2013 10:03 AM

Page 3, Q12. We want to know what other challenges parents of disabled children face, which might make it more difficult for them to access a support service. Please tick all that apply:

1	I rely on a carer to take me places, so internet access, phone consultations and home visits are vital.	May 27, 2013 11:06 AM
2	Having another child under 3, it's quite difficult to get childcare to attend meetings alongside working.	May 27, 2013 11:06 AM
3	Working and caring for a disabled 15-year-old has many barriers; not much support in or out of work for carer.	May 27, 2013 11:04 AM
4	I have high blood pressure and have been prescribed long term medication	May 27, 2013 11:02 AM
5	My mother is elderly plus my husband has high functioning autism which brings more complications rather than any kind of practical or emotional support	May 27, 2013 11:01 AM
6	I need to be able to go out to work or evening leisure knowing that my daughter is having fun with a friend and not worrying about me or vice versa	May 27, 2013 11:01 AM
7	Seeking help - carers for children	May 27, 2013 11:00 AM
8	Overwhelmed by things to do in relation to my child - filling in forms, making appointments/attending appointments, looking for solutions to issues, fighting for resources challenging professionals.	May 27, 2013 10:57 AM
9	Despite being able bodied and strong minded it is very/extremely difficult caring for a child with "hidden" disabilities. Constant slog. Draining, challenging rollercoaster life. Unpredictable. Support is minimal. (stretches resources)	May 27, 2013 10:55 AM
10	I have been a single parent since my child was born almost and i suffer from chronic back pain and severe migraine attacks which impact my life a great deal.	May 27, 2013 10:54 AM
11	I am a deaf mother. I have three other children to care for beside my disabled child.	May 27, 2013 10:51 AM
12	Time	May 27, 2013 10:48 AM
13	Unfit to drive at times (can't sit for long). Could do with a lift to meetings / more likely to go with support.	May 27, 2013 10:46 AM
14	Me and my partner both work. My partner full time, myself part time (cannot claim child tax or working tax credit). VERY UNFAIR.	May 27, 2013 10:42 AM
15	Working and caring for a disabled child. Supporting two children, one without any special needs.	May 27, 2013 10:42 AM
16	- I don't have a close, supportive network or family - I anxiety, panic attacks and depression - My child's sibling has got an anxiety disorder now You need to understand that having ONE disabled child is incredibly difficult for families. Many parents are anxious, depressed, isolated, frightened. Many relationships are collapsing under the strain.	May 27, 2013 10:41 AM
17	Because you have to get info from all over the place not just one stop does it all, it's very confusing and time-consuming for parents who don't have much time to go round and are constantly shattered.	May 27, 2013 10:37 AM

Page 3, Q12. We want to know what other challenges parents of disabled children face, which might make it more difficult for them to access a support service. Please tick all that apply:

18	A lot of what seems to happen, happens during school hours and I work, so that makes accessing support difficult due to time constraints.	May 27, 2013 10:31 AM
19	I work to support my family. Sometimes feel either working or looking after kids. No other time to help others! Or self! Everything seems to assure you can't work and have disabled kid - all daytime meetings. Enough with school and health appointments!	May 27, 2013 10:28 AM
20	I have more than one child, although only one is disabled the other is very young	May 27, 2013 10:23 AM
21	Half of the time it's not having enough hours in the day to be able to get the help you need or just feeling exhausted all the time and having to be around 24/7 for the needs of the children.	May 27, 2013 10:19 AM
22	I have a stammer and find using the telephone difficult. I have a degree of Asbergers myself as does my son.	May 27, 2013 10:12 AM
23	Just day to day life !	May 27, 2013 10:11 AM
24	I work (single parent) so desperately want to go to meetings and forums but can't get time off work as they do not understand and are not supportive.	May 27, 2013 10:10 AM
25	I don't have a printer to print download information,I'm not twitter or facebook 'technology friendly' only Basic IT skills. Confusing when social services/council rearrange services names/ location/frequently	May 27, 2013 10:08 AM
26	Life can simply be too exhausting and the thought of yet again answering more questions and filling in forms seems more than you can cope with	May 27, 2013 10:05 AM
27	Being a single parent with no social support network is hard.	May 27, 2013 10:03 AM
28	None of these apply now but for 4 years until last May I was also the primary carer for my elderly father-in-law	May 27, 2013 10:03 AM
29	Feeling guilty about a child's behaviour so becoming isolated feeling too tired to ask for help not knowing what is available so therefore not asking for it	May 27, 2013 10:01 AM
30	Worn out and lack of sleep	May 27, 2013 10:01 AM
31	I do not drive	May 27, 2013 9:59 AM
32	difficulty in respect of getting the correct appropriate dept I need to seek to speak to.	May 24, 2013 12:26 PM

Page 3, Q13. Have we missed anything? Please use this text box for any additional comments about the provision of information, advice and support for parents of disabled children.

1	More support for people who work and the challenges they face to stay in work and to find correct support for them and their child.	May 27, 2013 11:04 AM
2	Parent Carer Support Grop has been excellent at bringing families with children of various disabilities together. The newsletter has very useful information. The committee member are to be congratulated on their hard work.	May 27, 2013 11:04 AM
3	I just need counselling for myself and my daughter as we find it difficult to talk to each other. so any sort of help would be grateful.	May 27, 2013 11:01 AM
4	accessing swimming lessons at affordable rates. Services where equipment such as toys, playkits, bikes, trampolines, play equipment may be available to hire for free.	May 27, 2013 11:00 AM
5	Provision for our son with Diabetes is good with most needs met and an improving service. However, it is the opposite for our son on the Autistic Spectrum. The system doesn't meet his speech and language needs. We regularly meet with a lack of understanding about his condition and needs. The state secondary school, although good, struggle to support sufficiently at times as they aren't sufficiently funded or trained for individual children's needs. Trying to support our son on the Autistic Spectrum is our biggest challenge and worry. Note - we met with a Pyschologist in October 2011 at Ryegate to discuss issues and they suggested that intervention was required and we are still waiting to hear from them. Obviously we have had to deal with the issue without the support that we were told was appropriate.	May 27, 2013 11:00 AM
6	Something needs to change!!!	May 27, 2013 10:59 AM
7	more effort should me made empathising with deaf people rather than taking advantage of their natural communication difficulties	May 27, 2013 10:57 AM
8	I am a Deaf mother unable to hear a telephone nor able to make phone calls. Would struggle in group meetings, big meeting would need a BSL interpreter.	May 27, 2013 10:51 AM
9	Re. question 9: Good to get different views/opinions in different places. Okay as long as same information is not duplicated over and over from different sources. As an unfit carer feel isolated and out of the "loop". Plenty is there if you are fit and able to go / able to sit and surf the internet for a while and have a more able disabled child. Otherwise both you (the main carer) and the disabled child are neglected. Carers who have no family support and no good friends who help or call in to support the disabled carer.	May 27, 2013 10:46 AM
10	Very confusing with too many agencies who do not communicate with each other. MAST team are unable to obtain any information from Ryegate.	May 27, 2013 10:42 AM
11	I wish there was ONE place that did everything and knew everything, that had flexible times to contact them. Also if you are told what help you can get, not parents having to find out what help is available. Like benefits, you claim one but you're not told what else you can claim. You have to fight for everything.	May 27, 2013 10:37 AM
12	Would like more support to what my child is entitled to (help in school), seems because my daughter hasn't got a statement because her behaviour is good, that she doesn't seem to be able to be in a small group for extra help because of costs there's not room for her. This seems unfair to me as	May 27, 2013 10:35 AM

Page 3, Q13. Have we missed anything? Please use this text box for any additional comments about the provision of information, advice and support for parents of disabled children.

	she has the difficulties but is unable to get the help she needs because she's well behaved?	
13	I would like to add the Council is cutting the support and benefits of disabled people even though they are vulnerable. So I am not sure what the Council wishes to achieve from this questionnaire?	May 27, 2013 10:32 AM
14	As a parent of a disabled child it can often feel that practical solutions cannot be easily achieved due to policies and procedures not being "fit for purpose".	May 27, 2013 10:31 AM
15	I struggle with label disabled for my kids - it alienates me. They are mainstream, albeit all struggling, and so I wonder if this form is appropriate for me even though one child is in receipt of middle and low rate DLA -> school adamant won't even get statement or individual help though her mental health suffers without small, quiet, support and structured environment.	May 27, 2013 10:28 AM
16	social housing priority	May 27, 2013 10:27 AM
17	I use the local support group, as it fits in with family life and is easy to get to But if they didn't have the information, I have phoned you. You do a fantastic job, keep it up! Many thanks	May 27, 2013 10:17 AM
18	Thank you for being there x	May 27, 2013 10:15 AM
19	Would like advice on making a will to make sure no one takes advantage of my children when we are no longer around.	May 27, 2013 10:11 AM
20	Face to face and parental support is vital. You cannot get emotional and personal interaction from a website or newsletter they should be used to disseminate information. I have come so far doing things on my own but know after 9 years battling on my own, I now need support and SPCF in where I'll be going.	May 27, 2013 10:10 AM
21	Can we have a consistent provider for more than 1 year at a time keep changing name/location/source/provider eg What is SNIPPS now?	May 27, 2013 10:08 AM
22	I think it needs more qualified people to actually visit the homes of carers with a disabled child. I am a single mum and have raised my son on my own from birth, I haven't been able to work due to him having school difficulties and I cant get a blue badge a mobility car or anything that would help. Yet a couple can get everything including a mobility car and have full time jobs and are buying their home. Where is the fairness there.	May 27, 2013 10:07 AM
23	Perhaps that speech and language are cut and this is impacting the needs of deaf children whose first language is BSL (British Sign Language). There are also communication barriers for disabled parents who want contact for advice especially with local council.	May 27, 2013 10:06 AM
24	Information comes at you in bits. Quite often you find out about something you could have used years after it was needed simply because you didn't know it existed.	May 27, 2013 10:05 AM
25	I think there is a lot more available now than when my children were young but there is still room for improvement. Health services are oversubscribed so it is difficult to get appointments and impossible to see the same clinician each time. There is also an assumption that if you have a job and an income	May 27, 2013 10:03 AM

Page 3, Q13. Have we missed anything? Please use this text box for any additional comments about the provision of information, advice and support for parents of disabled children.

that you must be managing and don't need any input or support from services - very frustrating!

26	Get sign back open up at ryegate get more staff for sign. They are so good yet this service taken away from where its most needed	May 27, 2013 10:01 AM
27	Having one central place that understands how it all works or can direct to the correct contact	May 27, 2013 10:01 AM
28	The quality of the service would be very important to me. Need to know that I could trust the organisation eg confidentiality	May 27, 2013 10:01 AM