

Q1 Please tell us the first part of your postcode - e.g. LU7 or SG17

Answered: 155 Skipped: 1

#	RESPONSES	DATE
1	LU7	11/17/2019 5:30 PM
2	LU7	11/17/2019 5:05 PM
3	Mk45	11/17/2019 4:36 PM
4	Lu7	11/17/2019 3:55 PM
5	MK45	11/17/2019 3:39 PM
6	LU7 3AH	11/17/2019 2:36 PM
7	LU5	11/17/2019 2:17 PM
8	SG19	11/17/2019 2:06 PM
9	Mk45	11/17/2019 1:42 PM
10	Lu7	11/17/2019 1:23 PM
11	Mk45	11/17/2019 1:22 PM
12	Mk45 4EB	11/17/2019 1:16 PM
13	Mk45	11/17/2019 12:50 PM
14	Lu6	11/17/2019 12:42 PM
15	Lu7	11/17/2019 12:37 PM
16	LU5 5RH	11/17/2019 12:18 PM
17	MK45	11/17/2019 12:17 PM
18	Sg17	11/17/2019 12:06 PM
19	Lu7	11/17/2019 12:04 PM
20	Sg17	11/17/2019 11:53 AM
21	SG17	11/17/2019 11:28 AM
22	LU7	11/17/2019 10:42 AM
23	lu7	11/17/2019 9:58 AM
24	SG19	11/17/2019 9:25 AM
25	SG17	11/17/2019 9:21 AM
26	Lu7	11/17/2019 9:14 AM
27	LU6	11/17/2019 9:01 AM
28	Mk17	11/17/2019 8:38 AM
29	Lu5	11/17/2019 8:07 AM
30	Lu7	11/17/2019 7:54 AM
31	SG17	11/17/2019 4:32 AM
32	Lu5	11/16/2019 11:59 PM
33	Lu7	11/16/2019 11:43 PM
34	Sg16	11/16/2019 11:38 PM
35	LU6	11/16/2019 11:13 PM
36	Sg16	11/16/2019 11:02 PM
37	SG18	11/16/2019 10:54 PM
38	Lu6	11/16/2019 10:27 PM
39	Lu6	11/16/2019 10:25 PM
40	Sg16	11/16/2019 10:16 PM
41	Lu7	11/16/2019 9:47 PM
42	Sg19	11/16/2019 9:47 PM
43	SG18	11/16/2019 9:23 PM
44	MK45	11/16/2019 9:13 PM
45	Mk45	11/16/2019 8:55 PM
46	Lu7	11/16/2019 8:39 PM

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47	Lu7	11/16/2019 8:37 PM
48	Lu7	11/16/2019 8:37 PM
49	SG19	11/16/2019 8:31 PM
50	Lu7	11/16/2019 8:18 PM
51	Lu27fx	11/16/2019 8:11 PM
52	Lu6	11/16/2019 7:55 PM
53	lu4	11/16/2019 7:51 PM
54	Lu7	11/16/2019 7:34 PM
55	Lu4	11/16/2019 7:29 PM
56	mk45	11/16/2019 7:19 PM
57	Lu7	11/16/2019 7:12 PM
58	Mk45	11/16/2019 7:11 PM
59	LU5	11/16/2019 7:09 PM
60	Mk17	11/16/2019 7:09 PM
61	Lu5	11/16/2019 7:00 PM
62	lu5	11/16/2019 6:59 PM
63	lu6 1PN	11/16/2019 6:57 PM
64	SG16	11/16/2019 6:54 PM
65	Lu7	11/16/2019 6:53 PM
66	Lu7	11/16/2019 6:42 PM
67	SG18	11/16/2019 6:41 PM
68	SG16	11/16/2019 6:36 PM
69	LU7	11/16/2019 6:36 PM
70	LU7	11/16/2019 6:32 PM
71	SG5	11/16/2019 6:31 PM
72	Lu7	11/16/2019 6:30 PM
73	SG18	11/16/2019 6:26 PM
74	LU7	11/16/2019 6:21 PM
75	MK45	11/16/2019 6:20 PM
76	Sg19	11/16/2019 6:16 PM
77	Lu5	11/16/2019 6:09 PM
78	LU7	11/16/2019 5:46 PM
79	LU7	11/16/2019 4:38 PM
80	Mk45	11/16/2019 4:26 PM
81	LU7	11/16/2019 4:19 PM
82	Lu49ta	11/16/2019 3:43 PM
83	Lu5	11/16/2019 3:40 PM
84	LU7	11/16/2019 3:35 PM
85	Lu71fq	11/16/2019 3:35 PM
86	Mk45	11/16/2019 3:28 PM
87	LU7,	11/16/2019 3:23 PM
88	Lu7 3bz	11/16/2019 3:15 PM
89	Lu5	11/16/2019 3:14 PM
90	Lu6	11/16/2019 3:14 PM
91	LU5	11/16/2019 3:07 PM
92	Lu73xf	11/16/2019 2:58 PM
93	LU7	11/16/2019 2:19 PM
94	Lu7	11/16/2019 12:14 PM
95	LU7	11/16/2019 10:16 AM
96	LU3	11/16/2019 6:42 AM
97	Lu7 1hx	11/15/2019 7:47 PM
98	SG18	11/15/2019 2:29 PM

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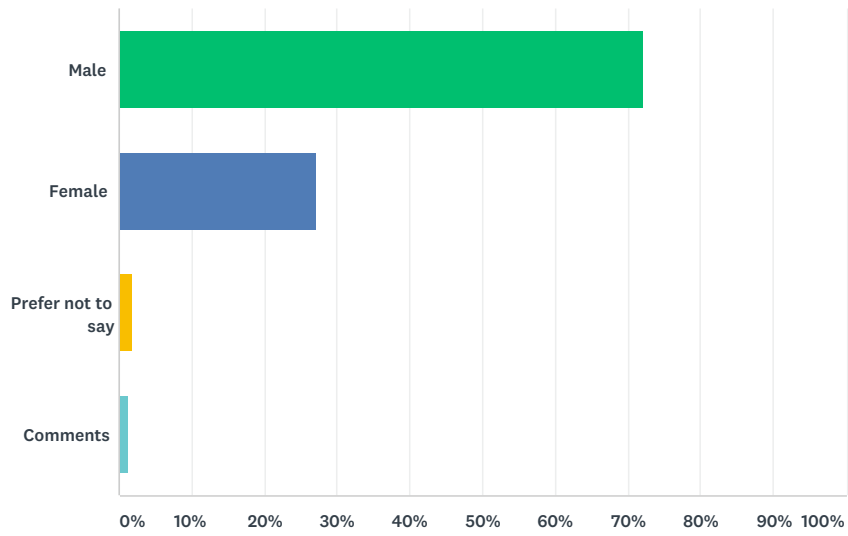
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101	Mk45	11/14/2019 5:16 PM
102	LU7	11/14/2019 11:12 AM
103	lu7	11/14/2019 10:10 AM
104	Mk45 5EL	11/13/2019 11:38 PM
105	LU5	11/13/2019 9:43 PM
106	MK45	11/13/2019 9:17 PM
107	Lu7	11/13/2019 8:57 PM
108	LU6	11/13/2019 8:26 PM
109	LU7 2UB	11/13/2019 7:58 PM
110	SG19	11/13/2019 7:49 PM
111	LU6	11/13/2019 7:41 PM
112	Lu7	11/13/2019 7:37 PM
113	MK45	11/13/2019 7:36 PM
114	lu7	11/13/2019 7:33 PM
115	Lu5	11/13/2019 7:23 PM
116	SG19	11/13/2019 6:41 PM
117	Sg19	11/13/2019 6:12 PM
118	Lu6	11/13/2019 4:44 PM
119	LU7	11/13/2019 3:20 PM
120	LU7	11/13/2019 3:07 PM
121	SG17	11/13/2019 1:18 PM
122	SG19	11/13/2019 12:40 PM
123	Sg5	11/13/2019 12:11 PM
124	Mk45	11/13/2019 12:08 PM
125	Lu7	11/13/2019 12:05 PM
126	lu7	11/13/2019 11:39 AM
127	LI54HY	11/13/2019 11:00 AM
128	LU6	11/13/2019 10:55 AM
129	MK45	11/13/2019 10:44 AM
130	LU5	11/13/2019 10:20 AM
131	SG19	11/13/2019 9:53 AM
132	SG5	11/13/2019 9:42 AM
133	MK45	11/13/2019 9:33 AM
134	Lu7	11/13/2019 7:46 AM
135	MK44	11/12/2019 7:42 PM
136	MK45	11/12/2019 7:23 PM
137	Lu7	11/12/2019 7:11 PM
138	Mk45	11/12/2019 6:30 PM
139	SG19	11/12/2019 6:12 PM
140	Lu72uw	11/12/2019 5:44 PM
141	Mk45	11/12/2019 4:10 PM
142	MK45	11/12/2019 4:03 PM
143	Lu7	11/12/2019 2:03 PM
144	Lu7	11/12/2019 2:02 PM
145	MK43	11/12/2019 1:58 PM
146	MK45	11/12/2019 1:35 PM
147	LU6	11/12/2019 1:26 PM
148	LU5	11/12/2019 1:23 PM
149	MK45	11/12/2019 1:22 PM

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150	LU6	11/12/2019 1:00 PM
151	Sg18	11/12/2019 12:28 PM
152	Lu5	11/12/2019 12:22 PM
153	Lu5	11/12/2019 11:53 AM
154	LU7	11/12/2019 11:37 AM
155	Lu7	11/12/2019 11:33 AM

Q2 What is your child/young person's gender?

Answered: 155 Skipped: 1

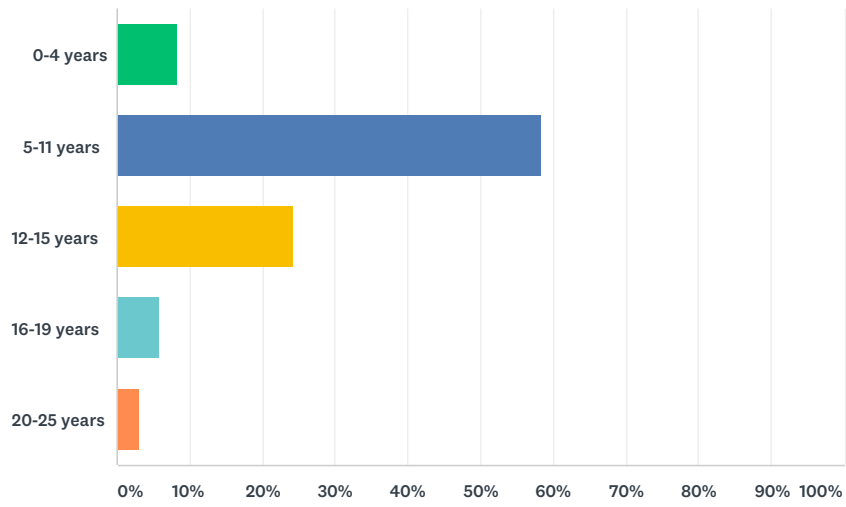


ANSWER CHOICES	RESPONSES	
Male	72.26%	112
Female	27.10%	42
Prefer not to say	1.94%	3
Comments	1.29%	2
Total Respondents: 155		

#	COMMENTS	DATE
1	2 boys	11/16/2019 6:31 PM
2	I have 2 SEN children	11/12/2019 12:22 PM

Q3 What age range is your child or young person?

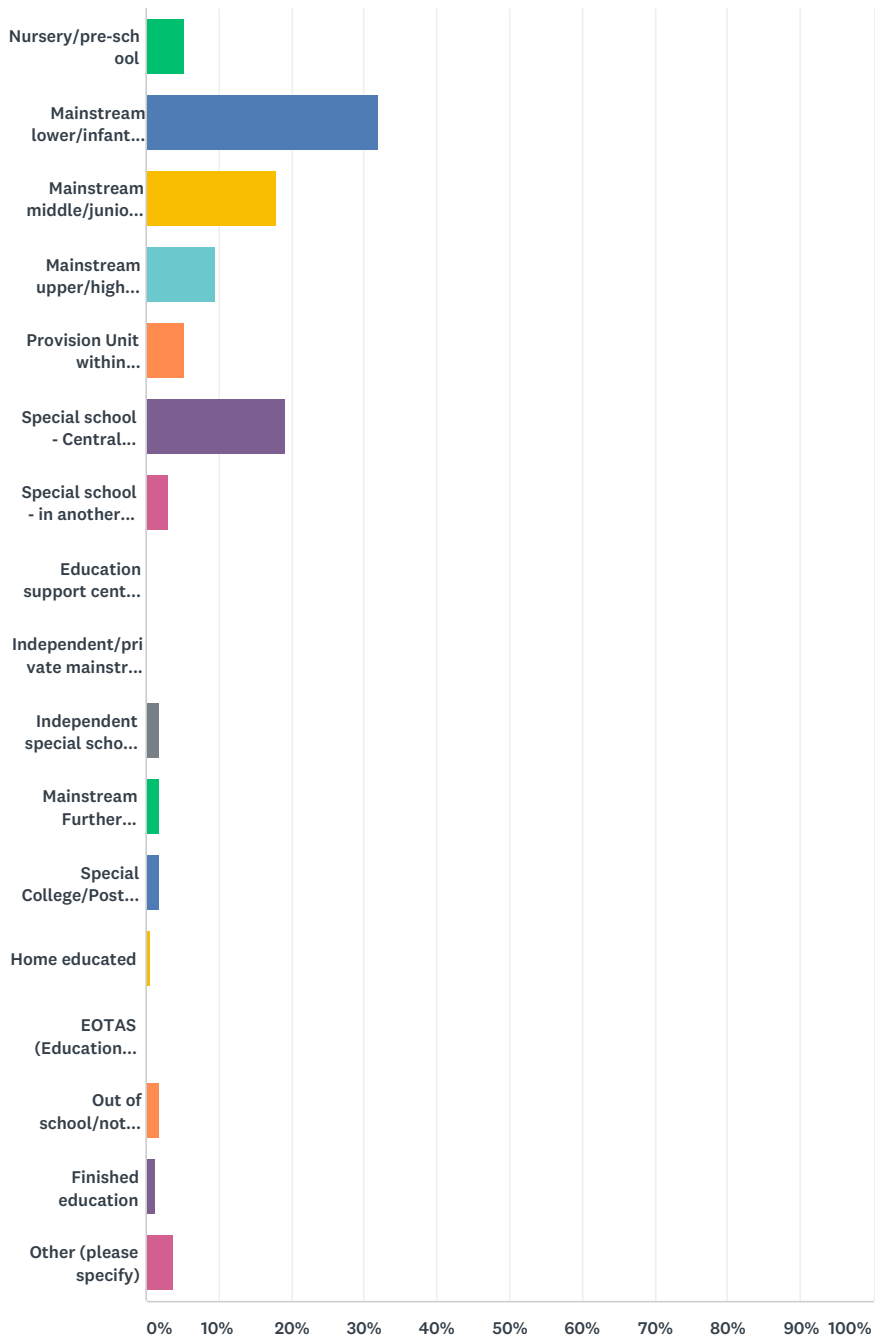
Answered: 156 Skipped: 0



ANSWER CHOICES	RESPONSES	
0-4 years	8.33%	13
5-11 years	58.33%	91
12-15 years	24.36%	38
16-19 years	5.77%	9
20-25 years	3.21%	5
Total Respondents: 156		

Q4 Which type of educational setting does your child/young person attend?

Answered: 156 Skipped: 0



ANSWER CHOICES	RESPONSES	
Nursery/pre-school	5.13%	8
Mainstream lower/infant school	32.05%	50
Mainstream middle/junior school	17.95%	28
Mainstream upper/high school	9.62%	15
Provision Unit within mainstream school	5.13%	8
Special school - Central Bedfordshire Council	19.23%	30
Special school - in another county	3.21%	5
Education support centre or pupil referral unit	0.00%	0
Independent/private mainstream school	0.00%	0

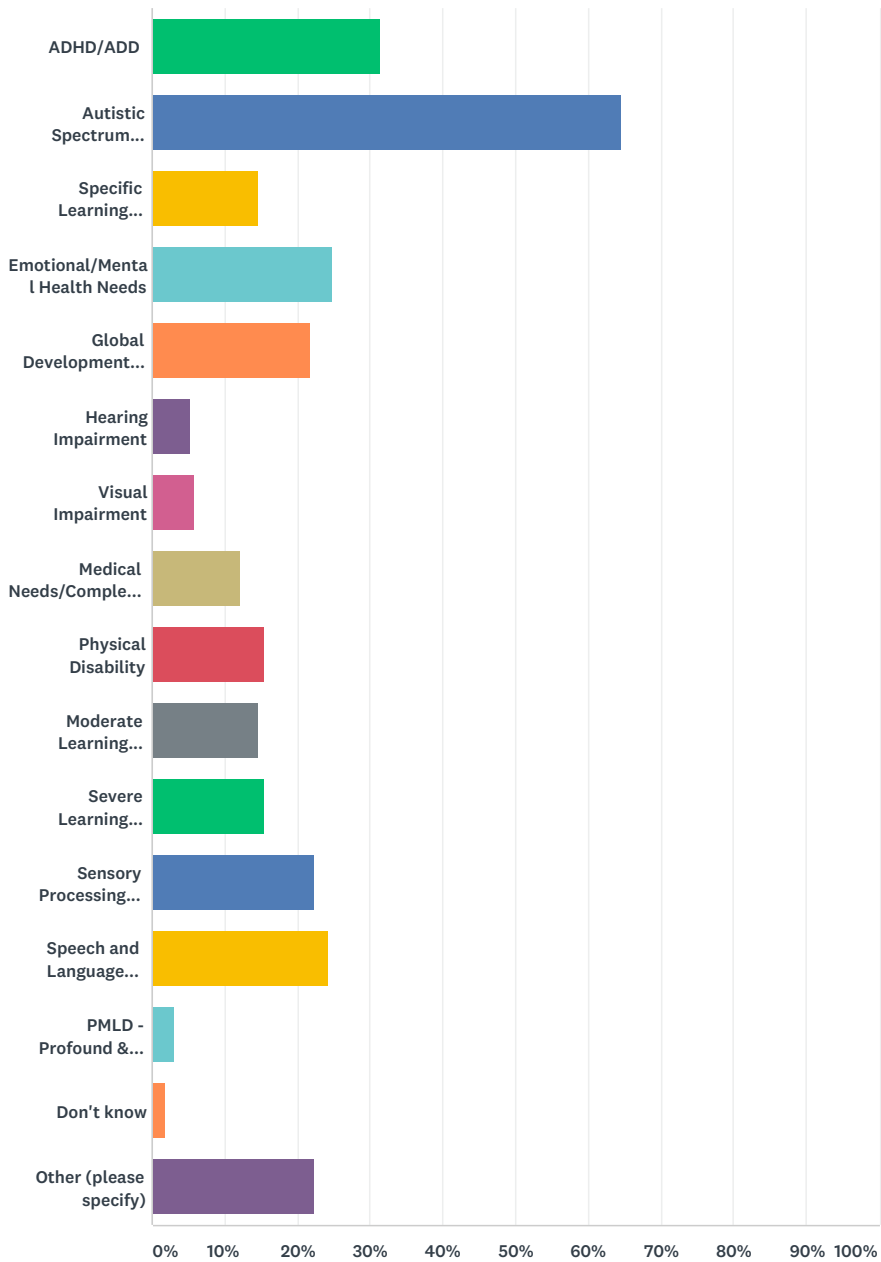
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Independent special school (out of county)	1.92%	3
Mainstream Further Education College/Post 16 Institution	1.92%	3
Special College/Post 16 institution	1.92%	3
Home educated	0.64%	1
EOTAS (Education other than at school)	0.00%	0
Out of school/not receiving an education	1.92%	3
Finished education	1.28%	2
Other (please specify)	3.85%	6
Total Respondents: 156		

#	OTHER (PLEASE SPECIFY)	DATE
1	Dual placed mainstream & specialist	11/17/2019 5:05 PM
2	Redborne	11/17/2019 1:42 PM
3	We have only just joined this unit, so some of my answers refer to the previous terms	11/16/2019 8:39 PM
4	Mainstream Primary school	11/16/2019 7:00 PM
5	Previously in Central Beds Special School until 2018	11/13/2019 10:55 AM
6	1:1 provided by Medical Services within SEND team.	11/13/2019 9:53 AM

Q5 What type of needs has your child been assessed as having? Tick as many as apply.

Answered: 156 Skipped: 0



ANSWER CHOICES	RESPONSES
ADHD/ADD	31.41% 49
Autistic Spectrum Disorder	64.74% 101
Specific Learning Difficulty ie. Dyslexia, Dyspraxia, Discalculia, Dysgraphia	14.74% 23
Emotional/Mental Health Needs	25.00% 39
Global Development Delay	21.79% 34
Hearing Impairment	5.13% 8
Visual Impairment	5.77% 9
Medical Needs/Complex Health Needs	12.18% 19
Physical Disability	15.38% 24
Moderate Learning Difficulties	14.74% 23

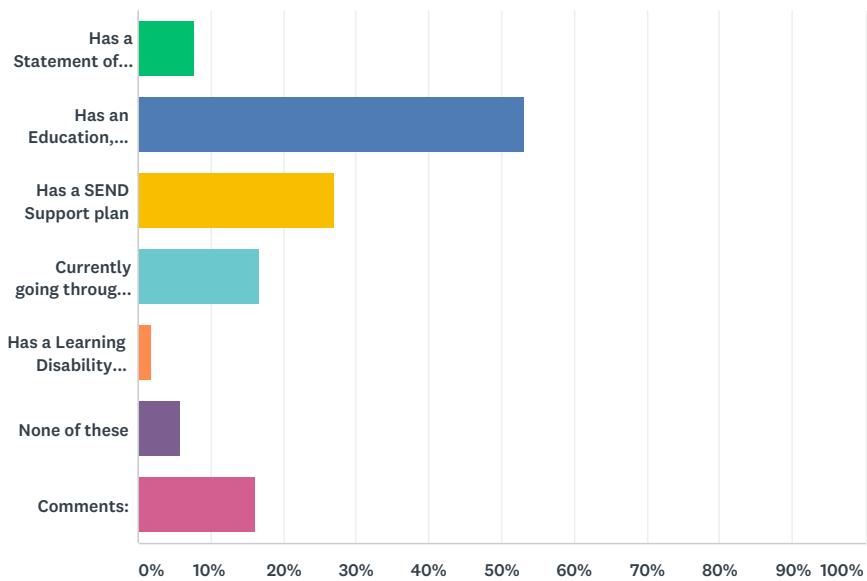
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Severe Learning Difficulties	15.38%	24
Sensory Processing Disorder	22.44%	35
Speech and Language Impairment	24.36%	38
PMLD - Profound & Multiple Learning Difficulties	3.21%	5
Don't know	1.92%	3
Other (please specify)	22.44%	35
Total Respondents: 156		

#	OTHER (PLEASE SPECIFY)	DATE
1	Irlen	11/17/2019 4:36 PM
2	Microcephaly KIF11	11/17/2019 3:55 PM
3	Learning difficulties due to Trisomy 21	11/17/2019 2:36 PM
4	Has a medical condition but more recently 3 professionals have identified an underlying concern.	11/17/2019 2:17 PM
5	FASD (Foetal Alcohol Spectrum Disorder)	11/17/2019 2:06 PM
6	Tourette's syndrome	11/17/2019 1:42 PM
7	Waiting assessment for ADHD and autism	11/17/2019 1:23 PM
8	Irlen syndrome	11/17/2019 12:50 PM
9	Tourettes OCD	11/17/2019 11:53 AM
10	Downs Syndrome Hypo thyroid Continence issues caused by slow pan colonic transit	11/17/2019 11:28 AM
11	Awaiting official diagnosis, expecting Aspergers - ASD	11/17/2019 10:42 AM
12	GAD Onset sleep association difficulties Defiant behaviour	11/17/2019 4:32 AM
13	Anxiety and attachment	11/16/2019 10:54 PM
14	Anxiety Behavioral issues	11/16/2019 10:16 PM
15	Currently being assessed for ASD	11/16/2019 9:23 PM
16	Unmet ongoing speech needs, having been discharged when the service was chronically understaffed. Unmet need for occupational therapy as recommended in the initial EHCP assessments 18 months ago and further evidenced by Helen Robinson prior to him moving to a special provision.	11/16/2019 8:39 PM
17	Awaiting an ADOS test	11/16/2019 8:37 PM
18	Epilepsy	11/16/2019 7:19 PM
19	1 x hyper mobility 1 x 3 yrs below age expected	11/16/2019 6:31 PM
20	Still under assessment. ADHD likely but not confirmed.	11/16/2019 4:38 PM
21	Waiting on Aspergers diagnosis	11/16/2019 3:14 PM
22	Williams Syndrome	11/15/2019 2:29 PM
23	The local CDC are refusing to see him.	11/13/2019 8:57 PM
24	Auditory Processing Disorder	11/13/2019 7:58 PM
25	Sotos syndrome	11/13/2019 7:37 PM
26	Rubenstein Taybi Syndrome	11/13/2019 10:55 AM
27	Hyper mobility syndrome	11/13/2019 10:20 AM
28	High Social and personal Anxiety, Eating disorder continued following anorexia for 3 years.	11/13/2019 9:53 AM
29	PDA traits SpLD	11/12/2019 7:23 PM
30	Social communication	11/12/2019 2:03 PM
31	All are suspected and currently under investigation	11/12/2019 2:02 PM
32	Down Syndrome	11/12/2019 1:58 PM
33	Challenging and violent behaviour	11/12/2019 1:23 PM
34	Hypermobility Ehlers Danlos Syndrome & POTS	11/12/2019 1:22 PM
35	Cerebellar ataxia	11/12/2019 12:22 PM

Q6 Which of the following apply to your child/young person:

Answered: 156 Skipped: 0



ANSWER CHOICES	RESPONSES
Has a Statement of Special Educational Needs	7.69% 12
Has an Education, Health and Care Plan (EHCP)	53.21% 83
Has a SEND Support plan	26.92% 42
Currently going through the assessment process	16.67% 26
Has a Learning Disability Assessment	1.92% 3
None of these	5.77% 9
Comments:	16.03% 25
Total Respondents: 156	

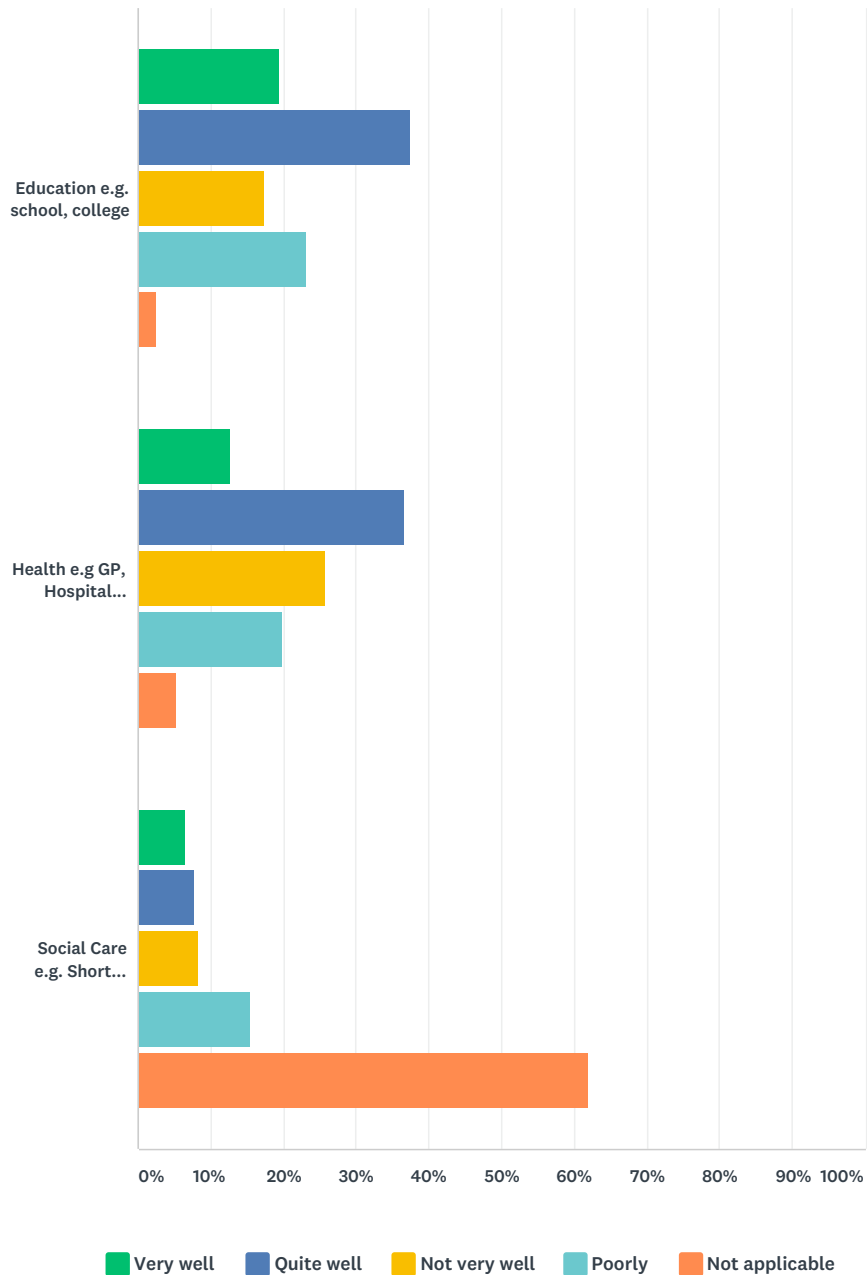
#	COMMENTS:	DATE
1	School do not support EHCPs and will not do regular iep reviews or even call/ acknowledge the plan an iep	11/17/2019 4:36 PM
2	EHCP in progress	11/17/2019 3:55 PM
3	Spoken to Psychologist attached to London hospital where medical care has been transferred. Awaiting whether child is on waiting list for Cognitive Assessment. GP appointment takes around 4 weeks. Hoping child will attend the next GP appointment booked so we can ask for a Cognitive Assessment via Edwin Lobo/equivalent locally.	11/17/2019 2:17 PM
4	Awaiting the draft week 17	11/17/2019 1:42 PM
5	I have to say I don't know, I still haven't received it from the school Or any other paperwork. She left the middle school with a Sen Profile and this still has been implemented or correctly passed to teachers	11/17/2019 12:17 PM
6	Long absences from school due to serious illness.	11/17/2019 9:21 AM
7	School refuse to do a plan as child is not behind educationally and masks behaviour at school	11/17/2019 4:32 AM
8	Application for ehcp been submitted	11/16/2019 10:54 PM
9	She had an ILP at lower school but support at her current school had been 'ad hoc'.	11/16/2019 10:25 PM
10	I	11/16/2019 9:13 PM
11	Has a IEP in school, and currently going through EHC needs assessment	11/16/2019 7:00 PM
12	Please check whether CBC ever finalises anyone's EHCPs.	11/16/2019 6:59 PM
13	I do feel he needs a EHCP but these are hard to get put in place	11/16/2019 6:53 PM
14	Both children have ehcp	11/16/2019 6:31 PM
15	Had IEP now SEND support plan at new school. Impossible to get schools to apply for EHCP despite complex needs.	11/16/2019 4:19 PM
16	Supposed to have IEP is under SEND	11/16/2019 3:15 PM

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17	Should have one but has not had it finalised and sent back since review in February this year (2019), despite numerous requests by us and our social worker	11/15/2019 2:29 PM
18	.	11/14/2019 8:57 PM
19	Apparently SEN stage 2 but no IEP in place, excluded from school at present	11/13/2019 8:57 PM
20	I will be applying for an EHCP.	11/13/2019 6:41 PM
21	Along with sensory processing disorder	11/13/2019 12:08 PM
22	We are appealing the SEND decision at tribunal on the 10th December as they want to reduce the hours of special needs schooling my son gets based on nothing but budget.	11/13/2019 11:39 AM
23	The plan is not finalised by CBC and has taken 18 mths to get to this stage from initial request for assessment.	11/13/2019 9:53 AM
24	Awaiting EHCP	11/13/2019 9:33 AM
25	Applied for assessment of EHCP and was rejected so waiting to reapply as missed deadline for filing mediation certificate	11/12/2019 1:22 PM

Q7 Please tell us how well you think your child/young person's needs have been identified by:

Answered: 156 Skipped: 0



	VERY WELL	QUITE WELL	NOT VERY WELL	POORLY	NOT APPLICABLE	TOTAL	WEIGHTED AVERAGE
Education e.g. school, college	19.35% 30	37.42% 58	17.42% 27	23.23% 36	2.58% 4	155	2.52
Health e.g. GP, Hospital specialist, wheelchair services, SALT, OT, Continence services	12.82% 20	36.54% 57	25.64% 40	19.87% 31	5.13% 8	156	2.68
Social Care e.g. Short breaks, respite services, residential and supported living	6.45% 10	7.74% 12	8.39% 13	15.48% 24	61.94% 96	155	4.19

#	COMMENTS	DATE
1	No support or info offered	11/17/2019 4:36 PM

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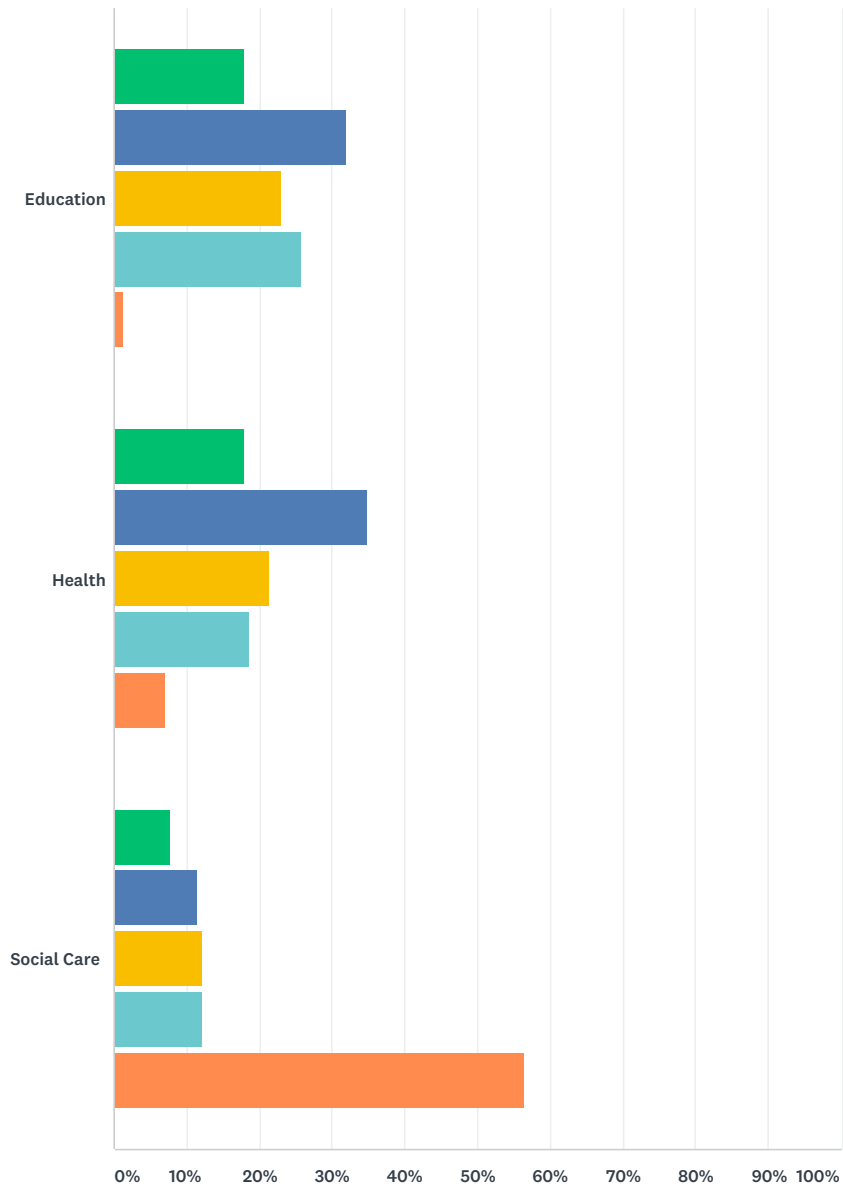
2	At the end of the academic year 2017/2018, I deregistered my daughter from her mainstream setting at Heathwood Lower School, due to a particularly bad year of not being cared for well. I could not get my child into an appropriate setting, and I did not feel supported by SEND provision. I home educated reluctantly and in January, I knew I was not coping with the situation. I contacted social services, who agreed that without any support around me, I was not coping well. However, I did not meet the criteria for them to get involved. The lack of social workers around meant that my family did not qualify for help, despite the fact that I was at that point severely suffering with my mental health. This was not a healthy environment for my children to be growing up in. Yet, there was no help or support available.	11/17/2019 2:36 PM
3	child's medical care has been moved to a London hospital	11/17/2019 2:17 PM
4	Firstly, this assessment is based on a provision my son attended (Ardley Hill Autism Provision) prior to moving to his new special school in September 2019.	11/17/2019 12:04 PM
5	Professionals have listened to my concerns and done relevant assessments but I don't feel that their recommendations have adequately reflected my child's true needs. They have provided general advice and strategies in their reports following assessments but needs have not been detailed enough and provision required to meet those needs not specified or quantified. I have felt that local authority professionals have been reluctant to specify any provision with a possible cost attached and therefore important provision required to meet my child's needs have been left out of reports. Professionals for OT, Soeich and Physio seem to assess make general recommendations and immediately discharge from service.	11/17/2019 11:53 AM
6	Never been offered respite or a break he is now 20	11/17/2019 8:07 AM
7	Blame put on parents for child's needs, too much focus on how parent is bringing up the child rather than why the child presents as they do. Due to masking at school, parents deemed as liars. Huge waiting times for cdc	11/17/2019 4:32 AM
8	School were concerned for 2 years before seeking specialist advice. SALT was not helpful and just looked for ways to discharge	11/16/2019 11:13 PM
9	Our gp did initial referrals but that is as far as it goes for above question. OT has been requested by school but nothing yet. Re schools the above rating is on the basis of current school - prior I would rate not very well	11/16/2019 10:54 PM
10	We had to pay for a private assessment as they needs we're not considered severe enough to warrant Ed Pych report and there is a lack of SPLD specialists in CBC.	11/16/2019 10:25 PM
11	He has continuing SALT needs and OT needs which are not being met despite us paying for private assessment to solidly evidence it. We have pressed SEN repeatedly to put in place the OT intervention which was recommended in the EHCP initial assessment, as have school, but even after seeking legal advice we have been met with at best, empty words. Very very poor. Luckily for Central Bedfordshire, we don't have the funds or the resources to initiate an appeal at the moment.	11/16/2019 8:39 PM
12	Social workers do not have the time or expertise to really get to know the young person and their needs, and the needs of their families.	11/16/2019 7:19 PM
13	My youngest daughter didn't have access to a salt for two years! She goes to a special school and is NV. She was seen by SALT in April 2017 then last month October 2019 after I PHONED and asked to talk to a SALT	11/16/2019 6:36 PM
14	Everything has had to be fought for.	11/16/2019 4:26 PM
15	Social worker very hostile and has a blame culture. Not helpful and doesn't put the child's needs at the heart of decision making. Very poor.	11/16/2019 3:28 PM
16	Have not applied yet	11/16/2019 3:07 PM
17	It has taken 7 years off basically no support, had to fight in the end. Not right!	11/16/2019 12:14 PM
18	Despite the efforts from the school I don't believe she gets enough support for therapies she desperately needs. SHe has been discharged from OT services, but has huge issues (mainly sensory) which impact on her daily life - e.g. she cannot eat. She has not seen a paediatrician for over 18 months and communications have to be carried out by e-mail. She has been discharged from the paediatric gastroenterologist at Addenbrooks despite being tube fed.	11/15/2019 2:29 PM
19	.	11/14/2019 8:57 PM
20	Education - we changed preschools 3 times before any support was implemented. Health - SALT have been good at identifying needs, however it's impossible to get an appointment. The paediatrician was not very good at identifying needs it took 2 and half years to get a diagnosis for my son.	11/13/2019 11:38 PM
21	Nothing available as undiagnosed	11/13/2019 8:57 PM
22	social services team have been excellent in their support	11/13/2019 7:49 PM
23	My son's school has not been supportive AT ALL when I have discussed getting my son to Edwin Lobo or an assessment. He was diagnosed with High Functioning Autism at age 3 at nursery and school do not think he needs an SEND plan.	11/13/2019 7:33 PM
24	Not had access to respite	11/13/2019 7:23 PM
25	Only just been given a social worker but she's seems to be trying to get things in place	11/13/2019 4:44 PM
26	pre-school were very good. Since starting lower school it has been an ongoing battle. My son tells us every day he hates school and writing.	11/13/2019 3:07 PM
27	Education - Previous Central Beds special School = Poorly (now in out of county School = very well)	11/13/2019 10:55 AM

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28	We only have a basic education in place for Maths, Science and English despite being in Yr 10. None of other subjects for GCSE's covered yet. Working with SEND and school to try and complete EHCP and get resources and support in place.	11/13/2019 9:53 AM
29	Lower school did not effectively identify his needs. Only his ADHD Specialist Nurse has been able to clearly understand his needs.	11/13/2019 9:42 AM
30	Lower school let him down but middle school have stepped up and supporting him	11/12/2019 2:03 PM
31	Still no overnight respite away from the home as nowhere can meet her complex health needs. Also even though her EHCP states that she should be seen by SALT termly (as a minimum) she has only been seen 3 times in 4 years!! Still no names SALT and no idea of when and if she will be seen again. Complaint has been put into Jo Drew several times and also to PALS but still getting nowhere. My daughter has no means of communicating. My daughter has come on massively in her physical development the last 3 years but this is because she regularly has input from a physio and they are always going in and updating her plan with school. Unfortunately, I feel if she had the same input from SALT over the last 3 years then we may be in a different place with her communication.	11/12/2019 1:58 PM
32	Social care responded to our tribunal hearing by starting section 37 enquiry's in to both off our children. This was done by a letter through our door by 2 social workers less than 48hrs after receiving the tribunal date. We was treated horrific by social care, which was apparent at the tribunal in which the LA was heavily condemned and which was upheld in out favour on all 63 point!!! I could go on about our mistreatment but I personally think it will make no difference!	11/12/2019 1:35 PM
33	Lark Rise is an exceptional school and has identified his needs very well with the help of outside professionals.	11/12/2019 1:26 PM
34	School were appalling - despite us flagging on entry to Reception (2 years ago) that we had concerns, it has taken multiple damaging and traumatic incidents - including one of our twins trying to kill himself at age 6, and the other seriously injuring us at home due to his violent and aggressive behaviour - for anyone to believe us and start doing anything. School are ignorant of the SEND Code of Practice, the local authority has no provision for Occupational Therapy for sensory processing needs, and local diagnostic teams do not acknowledge PDA so only go by very stereotypical presentations of ASD. CAMHS have refused to see both children twice, saying that they do not meet thresholds and that they do not work with children under the age of 11!!!!	11/12/2019 1:23 PM
35	His needs were well identified by his first mainstream school, Lark Rise. Sadly at Ardley Hill Autism Provision, they were not met.	11/12/2019 1:00 PM

Q8 Please tell us how well your views were taken into account when your child/young person's needs were identified by:

Answered: 156 Skipped: 0



Very well Quite well Not very well Poorly Not applicable

	VERY WELL	QUITE WELL	NOT VERY WELL	POORLY	NOT APPLICABLE	TOTAL	WEIGHTED AVERAGE
Education	17.95% 28	32.05% 50	23.08% 36	25.64% 40	1.28% 2	156	2.60
Health	18.06% 28	34.84% 54	21.29% 33	18.71% 29	7.10% 11	155	2.62
Social Care	7.69% 12	11.54% 18	12.18% 19	12.18% 19	56.41% 88	156	3.98

#	COMMENTS:	DATE
1	Offered lots of parenting courses	11/17/2019 4:36 PM
2	I feel lucky now that my daughter is in a setting where my views are taken into consideration. However, I feel that this is simply because she is now in a SEN setting. I do not believe that if she were in a mainstream setting, this would be the same.	11/17/2019 2:36 PM

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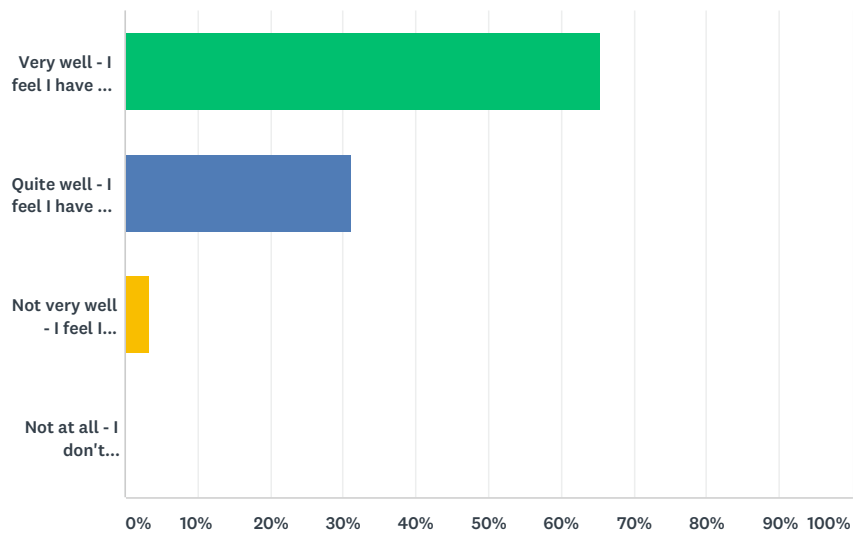
3	School extremely poor and not forthcoming with the truth about my son. My views only listened but not actioned on especially with ECHP's, only actioned basing on educational staff views. I had to do the fight and be elusive from school to get correct medical person that differs from same other professionals to be acknowledged. School only address the surface of a child differculties, they don't admit they not fully in depth spectrum trained and not long enough. Staff only follow their principles/headteacher rules based on there amenities. Parents attend numerous training seminars know more about spectrum disorders than schools who only say are trained but in action it's clearly shown they are not as shows more diagnosis on the child as they do each academic year. Currently in severe litigation as school not suitable as they won't admit to parents and nor raise to parent if parent not aware. Disgraceful as their image and reputation is more important than a child even in high society area in the central Bed borough.	11/17/2019 1:22 PM
4	It took 5 years and private assessments before the nhs would diagnose. Because she masks at school there is little help and we had to get a cognitive assessment to prove she was bright and there were significant barriers to her learning. The bridge is still not gapped.	11/17/2019 12:50 PM
5	No SALT at all, No OT at all for a child identified as needing it. Excuses of lack of staff or sensory OT not being commissioned actually given as excuses to not do anything.	11/17/2019 12:37 PM
6	My son received a poor quality of education in his provision at Ardley Hill. The staff were not ASD trained and the SEND team at CBC failed to monitor the provision for 2 years after they opened it. My son was kept on part time hours there for nearly two years, CBC failed to look into this after numerous phone calls. The safeguarding team at CBC got involved because the children in the provision were being locked in a 5 ft Square cupboard, during this investigation my son was assaulted by a teaching assistant, grabbed and thrown to the floor resulting in a head injury. The SEND team failed to monitor the provision even during an investigation. My son is currently on part time hours at his new school due to the trauma he experienced at Ardley Hill.	11/17/2019 12:04 PM
7	As above professionals have asked for My views and those of my child but these have not necessarily been acted on. In terms of my child's school placement our views and the views of educational professionals working with him were completely ignored even after repeated attempts to get them to listen, panel did not read through submitted information thoroughly enough if at all which resulted in central beds LEA SEN team identifying a completely unsuitable placement for his academic and social ability and it was only when his headteacher got involved and a tribunal hearing atranged that this decision was reversed. Shocking!!	11/17/2019 11:53 AM
8	We have never received social care	11/17/2019 8:38 AM
9	Blame put on parents for child's needs, too much focus on how parent is bringing up the child rather than why the child presents as they do. Due to masking at school, parents deemed as liars.	11/17/2019 4:32 AM
10	School pay lip service to parents views, are very reluctant to provide any information	11/16/2019 11:13 PM
11	Social care may be allocable to this case if you are talking about post adoption support who have recently become involved	11/16/2019 10:54 PM
12	Or views were well considered by the private Dyslexia specialist however school have not been forthcoming not do they consider her specific needs in relation to their differentiation or interventions e.g. she was put in phonics catch up sessions despite me explaining that this doesn't work as a method of reading or learning spellings (she's had phonics intervention since she was in year 2, if it was going to work it would have).	11/16/2019 10:25 PM
13	Lower school lied, denied issues, forgot about her diagnosis even when medication was involved	11/16/2019 10:16 PM
14	CAMHS have been a consistent and valuable support in ensuring he was placed appropriately.	11/16/2019 8:39 PM
15	Health professionals don't seem to have the time to consider how their medical treatment fits into my son's life as a whole and how it can affect his success at college and in other areas of his life	11/16/2019 7:19 PM
16	I feel that struggles are not taken seriously enough & we have had to reach crisis point before any action is taken.	11/16/2019 4:26 PM
17	My daughter respite for overnight is changing I haven't told her yet as she knows that she is meant to stay the same until she is 18 but it's not	11/16/2019 3:35 PM
18	Central Bedfordshire were very unsupportive. They did not look at my son's needs. All they were worried about was money and cost.	11/16/2019 3:28 PM
19	Despite our efforts she does not get enough therapy support at school (OT and Speech) We have tried to communicate with OT to voice our frustration and have simply been dismissed. I don't believe that group speech therapy is effective, and we don't get to know how best to help our child at home as there's no update from speech therapy.	11/15/2019 2:29 PM
20	Education - my views were not considered at 2 of the preschools, most including eyst blamed ASD on behavioural problems.	11/13/2019 11:38 PM
21	Moved Borough at age of 5, now in Bedfordshire services vastly improved support for us and our son	11/13/2019 7:49 PM

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22	Budget cuts are holding my child back. I said countless time that my child was not progressing and the Early Years Team found excuses to not support her properly. They are not really thinking of my child but of their budgets which means they cannot support my child properly because they are not thinking of her but of finances. Now she is way behind, the Early Years team are supporting her but it is too late as she is so far behind. She is 2.5yrs behind her peer group because of people trying to withhold support for her. Due to a lack of early intervention, we do not believe our child will last long in Mainstream because she is not so far behind so the system has not helped or supported her. Early intervention is key. I am so disappointed in the entire system for failing to support her. We pay taxes - and my other two children are fine but my disabled child has had minimal support. The system has let my child down - and made it much harder to stay in mainstream for all of primary because she is now starting from a weaker position.	11/13/2019 7:37 PM
23	We have not been supported at all.	11/13/2019 7:33 PM
24	In health, our son needs some surgery to extract a supernumerary tooth. The referral system between the dentist and the L&D seems completely useless. With his ASD, we wanted this resolved as quickly and smoothly as possible but ended up trapped in the system with no forward progress possible. It was only resolved when we got HealthWatch involved. In education, the school displays good intentions but seems to have insufficient staff/resources to deliver SEND support to match the SEND Support Plans	11/13/2019 3:20 PM
25	The school is good at listening but it is often led by us.	11/13/2019 3:07 PM
26	We have had to fight CBC to get the EHCP assessment and continue to do so to get the actual plan finalised. Initially only focused on education and took a lot of escalation within SEND team to get health and social care included. Still do not have final version of the plan that is being submitted for approval.	11/13/2019 9:53 AM
27	Conversations and meetings with the ADHD Specialist nurse have been very well understood. We feel like we are listened to and our child is well understood.	11/13/2019 9:42 AM
28	Very well by the school. Not so much by the LA.	11/12/2019 1:26 PM
29	Not applicable as all agencies were oblivious to our twins needs - we identified them and we have had to teach (and continually challenge) the involved agencies, especially their school, to follow the SEND Code of Practice and put things in place to help them both. Our views are taken into account because we are the only ones who know what to do!	11/12/2019 1:23 PM

Q9 How well do YOU understand your child/young person's needs?

Answered: 154 Skipped: 2



ANSWER CHOICES	RESPONSES
Very well - I feel I have a good understanding of most of their needs	65.58% 101
Quite well - I feel I have a good understanding of some of their needs	31.17% 48
Not very well - I feel I don't understand most of their needs	3.25% 5
Not at all - I don't understand any of their needs	0.00% 0
TOTAL	154

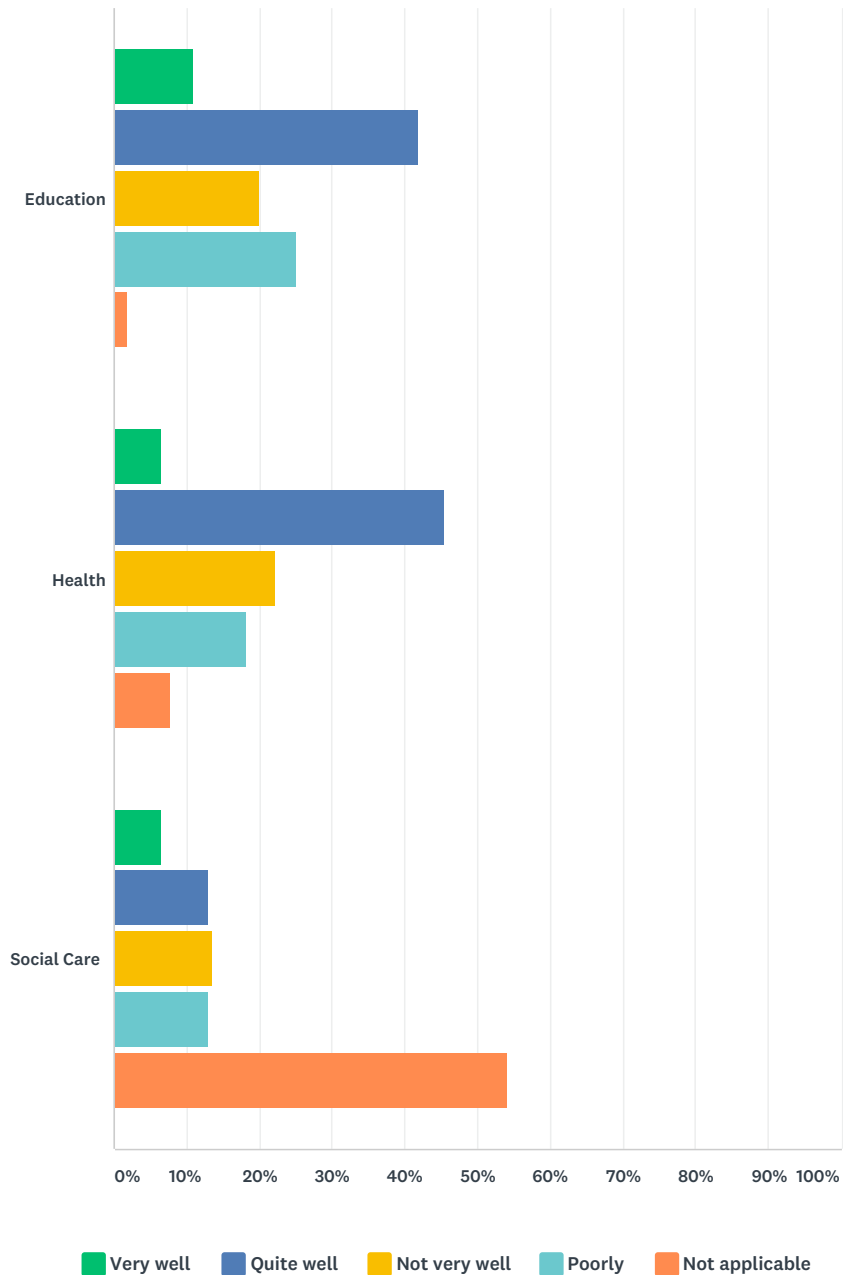
#	COMMENTS:	DATE
1	But I'm going to seminars from snap we are learning more that I wish someone had told us.	11/17/2019 4:36 PM
2	I am more naturally calm in dealing with the child, but would be useful to know and apply more different techniques. as we do not have a diagnosis of autism, we are unable to access courses/support. Teachers seem to shout at him, give him bad behaviour points, award detention. Then we get school refusal.	11/17/2019 2:17 PM
3	I have been proactive about finding out as much as I can but it's something we are still learning about. I know there are big gaps in my knowledge about how best to support him.	11/17/2019 1:23 PM
4	Attended numerous seminars and studied spectrum disorders with behavioural symptoms and the families children's act 2014 and the Send code. Also speaking with other parents experiences.	11/17/2019 1:22 PM
5	I have had to pay for private therapists to carry out and educate me on the areas identified but not actioned by the nhs.	11/17/2019 12:37 PM
6	I have made it a priority to learn as much about my child's difficulties as possible to ensure I know what is required to help him as this is needed to challenge and fight for the help he needs.	11/17/2019 11:53 AM
7	I'd like more help in order to help her	11/17/2019 10:42 AM
8	Self taught by attending courses run through autism Bedfordshire charity	11/17/2019 4:32 AM
9	I have done additional courses and research	11/16/2019 10:27 PM
10	This is because I am a teacher. I understand my daughter's needs more than teachers in her school. There seem s to be a lack of training and advisory teachers who can support staff in schools.	11/16/2019 10:25 PM
11	CAMHS therapists have helped us to understand our sons behaviour, but as he develops the situation is continually evolving, so we have to keep learning.	11/16/2019 8:39 PM
12	I find it quite hard to understand why my son can't control his emotions and has difficulty socially	11/16/2019 7:00 PM
13	.	11/14/2019 8:57 PM
14	Through private assessment and research we have found our answers.	11/13/2019 7:33 PM
15	I work in SEN.	11/13/2019 6:41 PM
16	I have been on many CBC courses and carried out much research on the internet.	11/13/2019 3:07 PM
17	We have lived with her health, education and social needs and support for 4 years now and at times have had to intervene with a number of professionals to ensure that the right level and protocol of support is provided for her.	11/13/2019 9:53 AM

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18	We need further professional input in order to be able to support him fully. This is not readily forthcoming.	11/13/2019 9:42 AM
19	I'm always trying to learn more, attend courses etc. to understand him better	11/13/2019 9:33 AM
20	Could do with extra help on ASD. Run support for for Bedfordshire for EDS & POTS.	11/12/2019 1:22 PM
21	Cant find training to get a greater understanding than basic. Training is either asd or adhd my son has both so training on both together would be helpful.	11/12/2019 11:33 AM

Q10 Overall, how well do you think Health, Education and Social Care understand your child/young person's needs?

Answered: 156 Skipped: 0



	VERY WELL	QUITE WELL	NOT VERY WELL	POORLY	NOT APPLICABLE	TOTAL	WEIGHTED AVERAGE
Education	10.97% 17	41.94% 65	20.00% 31	25.16% 39	1.94% 3	155	2.65
Health	6.49% 10	45.45% 70	22.08% 34	18.18% 28	7.79% 12	154	2.75
Social Care	6.45% 10	12.90% 20	13.55% 21	12.90% 20	54.19% 84	155	3.95

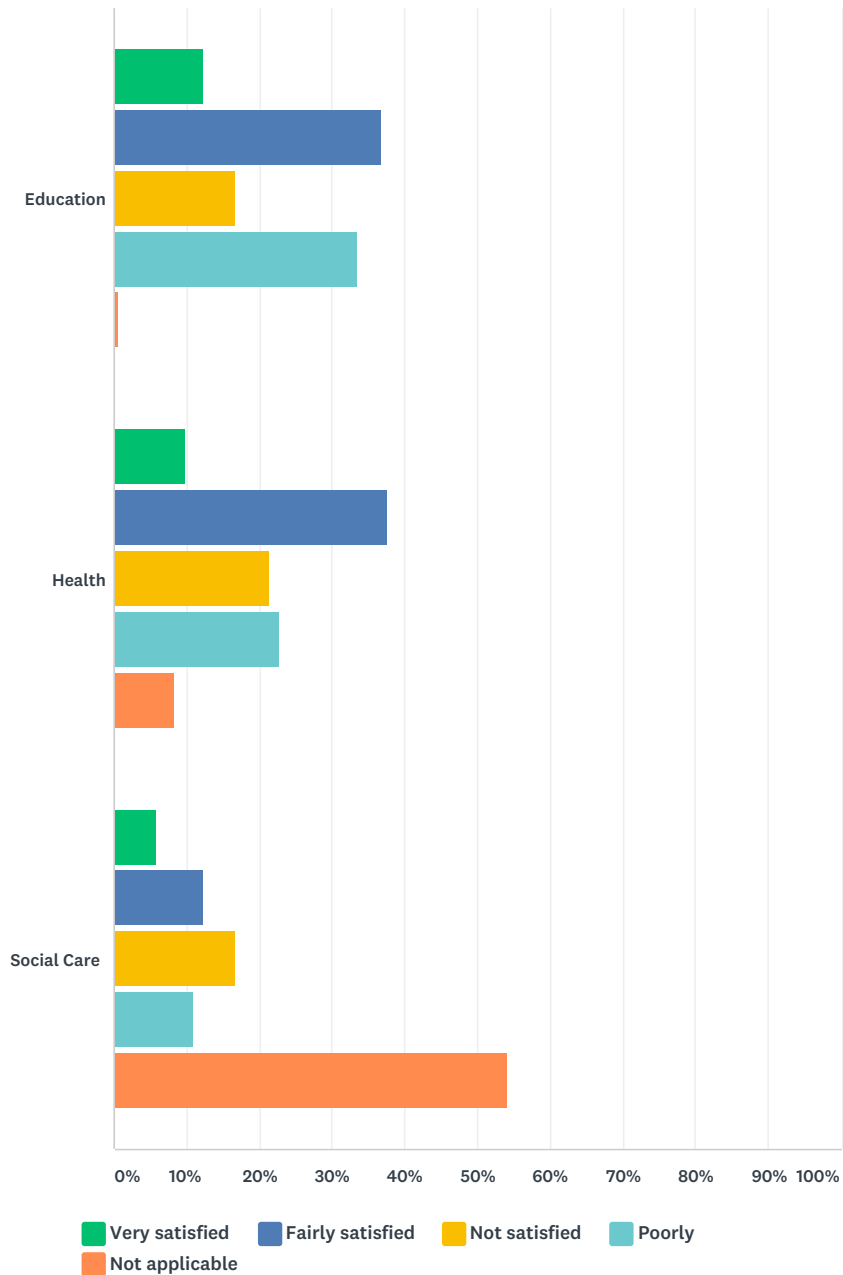
#	COMMENTS:	DATE
1	No support because she is in mainstream and does not cause them an issue so the barriers to learning are not recognised. She masks and issues from school are felt at home.	11/17/2019 4:36 PM
2	He is not looked at as a whole person. Education are mainly focused on his level of attainment literacy etc and aren't particularly interested with how his needs overlap with social interactions/health etc. Similarly health literally treat the presentin g 'issue' not really looking at him as a whole.	11/17/2019 1:23 PM
3	She has a diagnosis but no support.	11/17/2019 12:50 PM

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4	My sons social worker has become to understand him and his needs. Although these can't be met by DWP.	11/17/2019 12:37 PM
5	They have no understanding of children's needs. Send Transport team is an absolute disgrace, they do not put children's needs first, they change transport every year, our kids need continuity to feel safe.	11/17/2019 12:04 PM
6	My child's school And health professionals understand my child's needs overall quite well but this does not mean that he is getting all the help and support he needs as services are stretched or not available locally.	11/17/2019 11:53 AM
7	Great since middle school, lower school was a different story	11/17/2019 10:42 AM
8	We have spent a lot of time educating our child's educational setting on autism and bought private specialists in to support at school.	11/17/2019 8:38 AM
9	Girls with autism who do not have a learning disability are treated as being fine and therefore 'don't need support.' In fact the degree of emotional support for both child and family is very significant and completely unrecognised due to their 'ability' to 'cope' in school. Only support access provided is through Autism Bedfordshire and the Avenue. No understanding/recognition of spd Huge waiting times for cdc	11/17/2019 4:32 AM
10	They are reluctant to have outside agencies involved and just want to delay any actions until child moves onto High School	11/16/2019 11:13 PM
11	I've been waiting 2years + for speech and language therapy for treatment for an Expressive language disorder the delay has led to numerous additional mental health problems which I dont think would have happened otherwise	11/16/2019 10:27 PM
12	See above... Teachers tend to think if they give her worksheets on yellow paper then she'll be able to access the work.	11/16/2019 10:25 PM
13	We are in a different place this academic year, as the educational provision is a better fit. Last year things were extremely difficult and we are still recovering from the stress and frustration. It's still very early in the new placement, but things seem to be moving on positively.	11/16/2019 8:39 PM
14	Doctors and Social workers have so little direct contact with my son that they cannot possibly hope to understand his needs.	11/16/2019 7:19 PM
15	Only now when my son receives appropriate care and education out of county at a 24 hour curriculum school does my son receive what he needs; however, this took us to take LA to tribunal for our son to receive this. His new school understands his needs very well. But when he was in Central Beds, his needs were neglected and they were lost as to what to do with my son.	11/16/2019 3:28 PM
16	Education - we have an diagnosis and an EHCP, however it is a daily battle to get school to implement the support and understand my child's needs, the plans are not specific and not quantified from CBC so are not legally enforceable.	11/13/2019 11:38 PM
17	The system is flawed. The funding is so tight that the panel struggle to make just decisions.	11/13/2019 7:37 PM
18	We have been refused a referral to Edwin Lobo with our son.	11/13/2019 7:33 PM
19	Education - our son's particular ASD makes him non-disruptive and he has become well practised at work avoidance. This lets him slip under the teaching staff's radar as they are more focused on the more disruptive children in the class. External agencies have been in to observe him and have written reports with many suggestions but the school has not taken these into account very well.	11/13/2019 3:20 PM
20	The SENCO is well read and understands ASD. The problem is the delivery of the support.	11/13/2019 3:07 PM
21	My son has recently moved school due to his previous setting having little understanding how his 'behaviour' and ASD were linked. As a family the constant exclusions our tremendous pressure on us.	11/13/2019 11:00 AM
22	Education - Previous Central Beds Special School = Poorly (now in out of county School = very well)	11/13/2019 10:55 AM
23	The fact that we still don't have a plan which all the different professional departments have agreed on and taken in to account our input on our daughters behalf.	11/13/2019 9:53 AM
24	Again, we only receive excellent support from one healthcare professional.	11/13/2019 9:42 AM
25	Health now have a better understanding of my daughters needs because I raised a formal complaint with the CCG.	11/12/2019 7:23 PM
26	The school itself understands. CBC definitely doesn't!	11/12/2019 1:26 PM

Q11 How satisfied are you with the ongoing monitoring and assessment of your child/young person's needs?

Answered: 156 Skipped: 0



	VERY SATISFIED	FAIRLY SATISFIED	NOT SATISFIED	POORLY	NOT APPLICABLE	TOTAL	WEIGHTED AVERAGE
Education	12.26% 19	36.77% 57	16.77% 26	33.55% 52	0.65% 1	155	2.74
Health	9.74% 15	37.66% 58	21.43% 33	22.73% 35	8.44% 13	154	2.82
Social Care	5.81% 9	12.26% 19	16.77% 26	10.97% 17	54.19% 84	155	3.95

#	COMMENTS:	DATE
1	Does not really exists.	11/17/2019 4:36 PM
2	I feel this NOW! In the setting she is in.	11/17/2019 2:36 PM
3	There is really any health review. In school they do regularly review his SEND support plan.	11/17/2019 1:23 PM
4	Now he has hit sixteen everything has been withdrawn , speech therapy , learning support and his DLA . PIP not given , even though the assessor couldn't understand our child they stated he is not autistic enough (her words) to qualify for PIP	11/17/2019 1:16 PM

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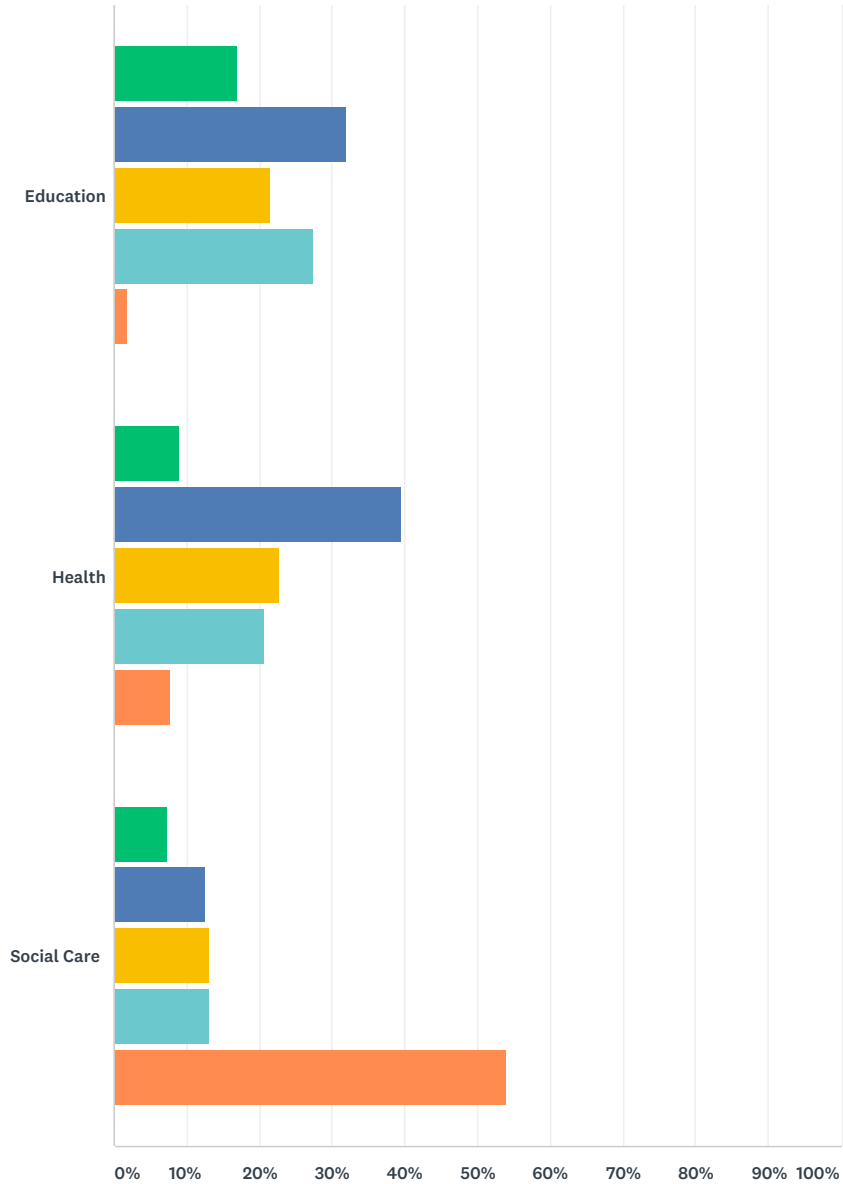
5	She does see Caroline Lewis at the CDC however this is more a therapeutic chat which is great.	11/17/2019 12:50 PM
6	Have the most contact with the social worker. Health do not follow up and have extremely long waiting times. All of our appointments are delayed. Education, school doesn't give enough opportunity to be informed of progress. Vital information is lost over summer. Previous teacher never told new teacher about SALT plans new teacher found out 10 weeks into new school year when it was parents evening.	11/17/2019 12:37 PM
7	I'm unsure at the moment because my son has been out of education and only just started his new school.	11/17/2019 12:04 PM
8	My child had a long wait to be assessed by CAMHS and is monitored regularly for his medication needs but therapies that could help improve his outcomes are not available to him locally. My child's annual review by his local CDC paediatrician is poor. He is on a waiting list to get his annual review appointment which is almost a year out of date! Completely unacceptable. Report detailing his annual review appointment never specifies the provision he needs at school to meet his needs even when I have requested it. I keep my child's school informed of his current needs. Only got updated EP assessment when going through tribunal process, prior to this LEA felt unnecessary even though last EP advice was 3 years out of date and child was changing educational placement from mainstream to special school provision.	11/17/2019 11:53 AM
9	We have never seen anyone from the local authority at EHCP reviews. His current EHCP for this academic year has still not been finalised by the council.	11/17/2019 8:38 AM
10	Education health care plan was not reviewed the 2 years he was in college and his support assistant was taken for another class, he had no support so left in the second year and was not supported to look for work or any training schemes.	11/17/2019 8:07 AM
11	Once given diagnosis, told we had to find own support for child even though paediatrician recognised that girls struggle mentally and without support will end up with other controlling disorders as teens. No social support as no ehcp. No understanding/recognition of spd Huge waiting times for cdc	11/17/2019 4:32 AM
12	It is impossible to gain any evidence of their processes and monitoring. No information is made available prior to meetings. Meetings don't address all of the issues as you are only allocated 30 minutes and often the SENDCo will not be aware of issues that parents raise	11/16/2019 11:13 PM
13	The new school are on board in terms of trying to assist our son - however we are all desperately in need of ehcp to give him the support he needs	11/16/2019 10:54 PM
14	At lower school, my daughter had termly meetings with targets set and reviewed. There had been no monitoring of her needs in Priory Academy. Despite huge amounts of intervention to pass her SATs, she didn't pass them and now she is in Year 7, there doesn't appear to be any further intervention. The school don't communicate very well generally and she gets no extra assessment or monitoring than a child without SEN.	11/16/2019 10:25 PM
15	Our Social Worker Stephen Heppolette is always prepared to listen and he is very supportive of our family as a whole unit. Social workers we have had in the past have not always appeared to understand issues faced and they had less urgency about them to support our family with problems we were facing. We feel now we have a good network of support from social care.	11/16/2019 9:47 PM
16	We understand that the Edwin Lobo Centre is overloaded with referrals and would like to say how excellent Dr Omisakin is despite that pressure. Our son has pronunciation problems which are directly impacting on his phonics learning and motivation to read, but has had no input despite our requests in reviews. We would like to reiterate the complete lack of service to meet the need our son has for occupational therapy as described in the recent assessment report. Both the previous school and preschool noted the need, it was also directly referred to in the EHCP assessment, but despite promises to previous SENCo and to me to 'look into it' etc etc we have been misdirected, emails from the SENCo were unanswered, phonecalls ignored. This is unprofessional of Central Bedfordshire and unacceptable given that denying his need will negatively affect the chances of success in the provision. Its like expecting a team to do the job with only half the tools. I will answer q12 on the present situation in the new placement.	11/16/2019 8:39 PM
17	EHCP updated annually by school but not by Local Authority. It seems they are only prepared to update the plan officially if there are huge changes. This means our plan, which is a legal document, is not up to date. No Health input since he was about 4 yrs old.	11/16/2019 6:36 PM
18	Social worker is incompetent. Health are only interested in children with phy dis; they have no criteria that is suitable for health problems with children with severe autism.	11/16/2019 3:28 PM
19	We have tried to communicate with OT to voice our frustration and have simply been dismissed. I don't believe that group speech therapy is effective, and we don't get to know how best to help our child at home as there's no update from speech therapy. She has not seen a paediatrician for over 18 months and communications have to be carried out by e-mail. She has been discharged from the paediatric gastroenterologist at Addenbrooks despite being tube fed.	11/15/2019 2:29 PM
20	Health - it is impossible to get an appointment with SALT, I rang twice a day for 2 weeks to get a review appointment for documentation for my sons Needs assessment as we had not had an appointment for over a year. The paediatrician signs you off after 6 months after your diagnosis. Education - most nursery's and preschools do not have qualified SENDCO so are unable to monitor need. There is no assessment done to reassess needs by an EP.	11/13/2019 11:38 PM
21	When we started at the school we were told that we would have quarterly meetings with the SEND. we have not had one. We had to ask for one.	11/13/2019 7:33 PM
22	Although the school are reviewing the plan, they absolutely refuse to put in place what he needs. Budget cuts is the excuse every time. They say he needs the support but are not prepared to pay for it and are refusing to apply for an EHCP assessment. I am being told he needs to be academically 4 years behind and 12 months of poor behaviour.	11/13/2019 6:41 PM

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23	Speech therapy appointments are getting further & further apart. Paediatrician appointments are 18 months/2 years apart. Our last echp review was Feb 2019 - we are still waiting for the paperwork from county! Echp reviews are supposed to be multi service but it's only ever the school representative & me!	11/13/2019 6:12 PM
24	Having looked at our son's writing work and having received his teacher assessments as 'expected', I find it hard to understand how. Our older son has been through the same school and also received 'expected' but comparing their work books, our older son was streets ahead at a similar point in his education (despite being the youngest in the class). Until year 4 we have never seen the results of any standardised testing (eg reading age, comprehension age). The school has not been seen by OFSTED since 2007 - who is monitoring the school?	11/13/2019 3:20 PM
25	The asthma nurse is brilliant (but unfortunately left our practise) - the service she offered was outstanding.	11/13/2019 3:07 PM
26	CBC have not completed his EHCP review paperwork for 2yrs but school are working with notes and we have a good relationship that overcomes their poor service	11/13/2019 12:40 PM
27	We as a family have had no support at all.	11/13/2019 11:00 AM
28	Education - Previous Central Beds Special School = Poorly (now in out of county School = very well) My child has a rare syndrome and very few specialist have even heard of, so it is a constant guessing game with her health but this is done via hospital consultants not Health in the EHCP	11/13/2019 10:55 AM
29	As above, we have had to get the SEND team to acknowledge and include health and social responsibility and activities in the (draft) EHCP and still not finalised.	11/13/2019 9:53 AM
30	Middle school have a better understanding of his needs and only one healthcare professional (as above) regularly reviews his needs.	11/13/2019 9:42 AM
31	My child needs speech and language therapy and occupational therapy. Currently these needs are not being met	11/13/2019 9:33 AM
32	Social worker moved on, no new social worker allocated instead given a support worker from TILT who did not listen to my child's needs. 2	11/13/2019 7:46 AM
33	Health more engaged due to a formal complaint raised to the CCG. Despite LA direction school have not implemented all recommendations citing school policy and academic progress as the priority despite difficulties in attending school. The LA are very poor at ensuring school meet recommendations and require chasing.	11/12/2019 7:23 PM
34	My sons new Paediatrician has been very supportive and helpful.	11/12/2019 6:30 PM
35	My son is now in a residential school were they understand and meet his very complex needs. Where as before this it was a very poor, due to social care's putting pressure on every other department involved with our sons care and education.	11/12/2019 1:35 PM
36	School monitor and assess well, but CBC don't complete EHCP annual reviews. My SENCO says lots of her EHCPs are over a year out of date and CBC still haven't made the amendments or sent a new draft. We have reviewed an EHCP for our son which hadn't been amended from the last review yet.	11/12/2019 1:26 PM
37	We seem to be stuck in a continual cycle of telling and retelling our story, plus assessments, but no one ever actually does anything - we are picking up the pieces for agency failure. We would like to be parents to our children and NOT their therapists!	11/12/2019 1:23 PM
38	My son was at the autism provision at Ardley Hill Academy. It was a new provision and the LA did not inspect or monitor it at all. They opened it and then took NO responsibility for it, or for the children given places there. Many parents ended up removing their children from the provision as teachers were shutting the children in a cupboard during autistic meltdowns, failing to safeguard them and not educating them or integrating them into the mainstream classes. The LA refuses to accept they were complicit in all of the failures at this provision and we are currently waiting for the Ombudsman to investigate the matter. Additionally, the LA don't follow statute on the timelines relating to EHCP annual reviews. Many people (including us) have reviewed a document that the LA have not yet updated a year later after the last review - they don't even let parents know whether they intend to amend, maintain or cease the plan, therefore frustrating the parents' right to appeal. It is very hard to amend a plan that hasn't even had last years' amendments completed yet!	11/12/2019 1:00 PM

Q12 How well do you think your child/young person's needs are met by the following service areas?

Answered: 155 Skipped: 1



Very well Fairly well Not very well Poorly Not applicable

	VERY WELL	FAIRLY WELL	NOT VERY WELL	POORLY	NOT APPLICABLE	TOTAL	WEIGHTED AVERAGE
Education	16.99% 26	32.03% 49	21.57% 33	27.45% 42	1.96% 3	153	2.65
Health	9.09% 14	39.61% 61	22.73% 35	20.78% 32	7.79% 12	154	2.79
Social Care	7.24% 11	12.50% 19	13.16% 20	13.16% 20	53.95% 82	152	3.94

#	COMMENTS:	DATE
1	No support and fighting to get autism advisory in.	11/17/2019 4:36 PM

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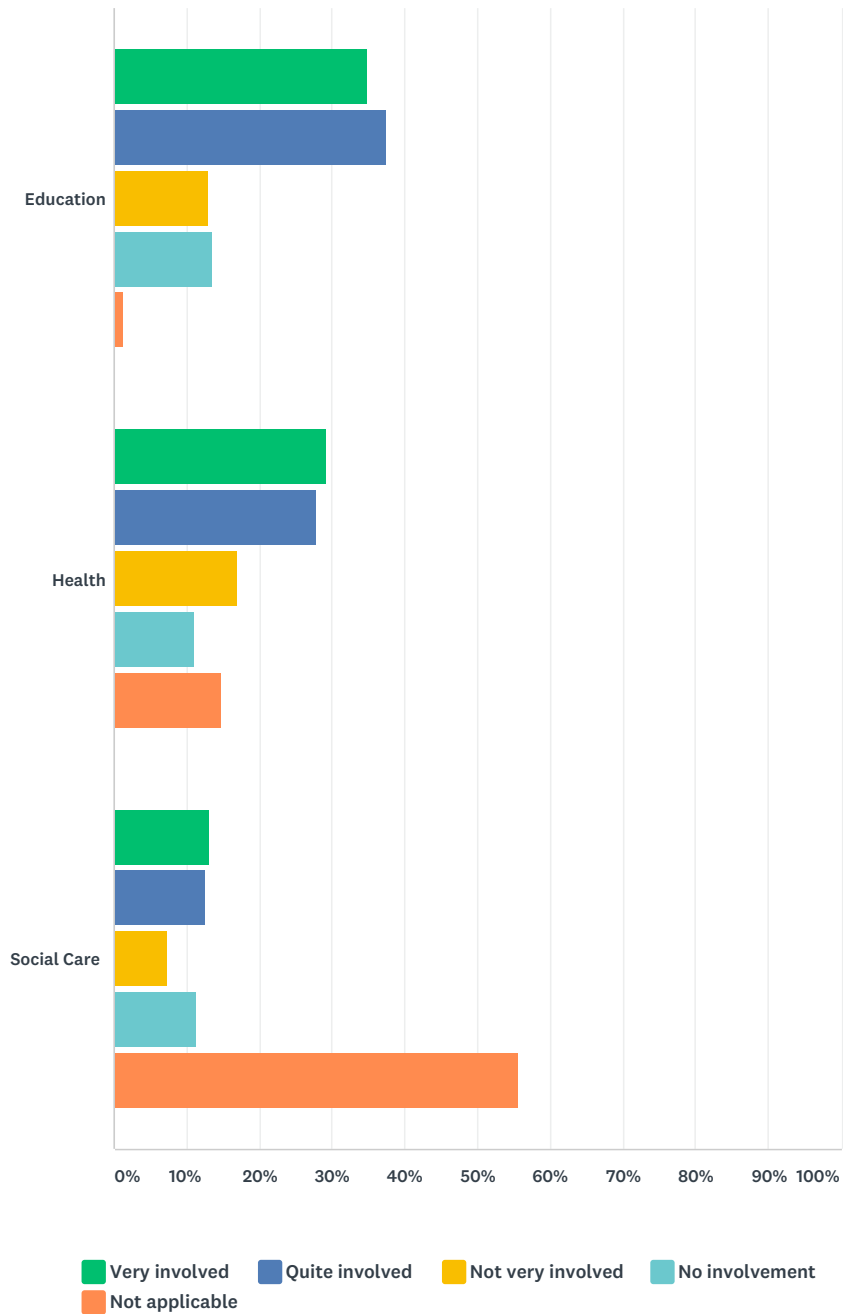
2	I feel that both of daughters needs should have been taken into consideration by social care during a very traumatic year and when my family needed support. My daughter has not been Seen by a paediatric consultant at Edwin Lobo since 2017. She was finally seen by a nurse from Edwin Lobo this year, but there was supposed to be an action taken which never was followed up. She gets seen by an endocrinologist, who thank Goodness is fabulous (from L and D) without whom, we would have no Consistent contact with any health teams. SALT has become so terrible that we pay for a private SALT for our daughter.	11/17/2019 2:36 PM
3	No one wants to know as he is now 18	11/17/2019 1:16 PM
4	She gets little support in any area. It takes pushing from us to get what she gets due to masking.	11/17/2019 12:50 PM
5	Health do not provide consistency. For example my son needed an EEG, we went for an appointment at L&D they couldn't do it because he is autistic. He will need to have it done in GOSH and be sedated. L&D said they refer this back to paediatrician who refers to GOSH but the paediatrician hasn't done this.	11/17/2019 12:37 PM
6	My experience has been horrendous. Send Team have lied to me, caused my son to lose out on a years education because there are no available places in provisions in CBC as it stands. My local Mp wrote to Sue Harrison regarding this matter. It took four months before CBC sorted out some tutoring for my son, this wasn't offered, I had to plead for this. CBC have not taken accountability for their failures regarding Ardley Hill, this has been dealt with by way of a formal complaint, it is now in the hands of 'The Local Government and Social Care Ombudsman. My son is so traumatised by the failures he's is needing specialist play therapy in his new school. It will take years for him to mend. He has lost out on 1.78 years of Education from the age of 5-7 under CBC Send team!	11/17/2019 12:04 PM
7	Emotional and wellbeing needs met well by school staff whilst in a mainstream ASD unit but academic needs could be better met by having appropriate resources. School staff know what is required to meet need but services and budget not available to meet the need.	11/17/2019 11:53 AM
8	As not a behavioural problem in school therefore not deemed as needing support. Had 6 sessions at CAMHS but three years ago and needs more but can't get in, keep getting refused. No understanding/recognition of spd Huge waiting times for cdc	11/17/2019 4:32 AM
9	School admit they have not had experience of my child's difficulty before, they are not happy if I go to outside agencies for advice	11/16/2019 11:13 PM
10	Have rated education not very well no reflection on the school just the lack of resourcing for kids like ours and the fight to push things forward. CDC and other services have been fine when seen but wait lists are Long and are woefully under resources. Haven't even been seen by chums yet.	11/16/2019 10:54 PM
11	There is a lack of understanding... And I think this is due somewhat to the lack of guidance and support from CBC. She is also not typical of other SEN children, her SEN doesn't impact her behaviour and she can 'get by' in class and she therefore gets lost.	11/16/2019 10:25 PM
12	I stated at her 2 years old checkup that something was different but I was told to wait till she was 7. She is now 10 and only just officially diagnosed 1 year ago and still being assessed. 7/8months inbetween appointments is shocking	11/16/2019 10:16 PM
13	Current educational provision is meeting mental health needs better and managing behaviour. Health score is reflective of the lack of SALT input	11/16/2019 8:39 PM
14	The speech therapy service is a joke and has been for years. It is very rare to have OT input. CBC do not recognise any sensory integration disorder until adulthood and provide no service whatsoever to children. Parents feel everything is a fight with CBC.	11/16/2019 6:59 PM
15	My sons severe anxiety is ignored and no help is given at all, he is referred to chums whi then take 7mths to give him any support.	11/16/2019 6:57 PM
16	My eldest daughter is doing well In her current school but she had to repeat year 4 In a another autism provision as her then school Ardley Hill Academy ASC failed her catastrophically. Her needs (new diagnosis of dyslexia) weren't identified she wasn't being taught properly and other children In her provision were violent which was making her highly anxious. She is flourishing in her new school but is only there for One year We then have to go to panel for the middle School provision and have a choice of an academy provision 30 MILES away, the one we removed Her from or a middle School provision practically next door which has no space. THERE ARE NOT ENOUGH AUTISM PROVISIONS IN CENTRAL BEDFORDSHIRE.	11/16/2019 6:36 PM
17	LA are totally incompetent. They are so disinterested in the best interests of the child and purely follow an agenda dictated by coatings. V poor.	11/16/2019 3:28 PM
18	Her school environment is good and She is very happy there. The main focus of learning is life skills which is great, but I fell that she has taken a step back from reading and numeracy which she was learning at her main stream school. There is not enough emphasis on implementing therapies such as speech, OT. We have tried to communicate with services at the CDC to voice our frustration and have simply been dismissed. There is not enough feedback from speech services and not enough focus is placed on talking sensory issues which are impacting on her daily life. She has not seen her paediatrician for over 18 months and communications are carried out by e-mail. SHE has been discharged from paediatric gastroenterologist eventhough she is tube fed.	11/15/2019 2:29 PM
19	.	11/14/2019 8:57 PM

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20	Health - SALT no appointments, are meant to come into review targets on EHCP although they haven't. We need a sensory integration assessment, highlighted on his EHCP, however there is no service in central Bedfordshire for this. Education - our ehcp assessment was not done in line with legislation from the ep and health sectors, all reports were extremely vague in content, not quantified, and do not meet my sons needs. Therefore educational setting is not meeting these needs.	11/13/2019 11:38 PM
21	The Chiltern school Kingsland campus always trying to put the blame on others. Staff have injured my child and the head teacher try's to blame it on students and lies to protect her staff. Goes against parents wishes and aspirations for their child and does as she pleases with our children.	11/13/2019 7:41 PM
22	Funding is preventing my child from being supported. She was declined an assessment for an ehcp for ridiculous reasons.	11/13/2019 7:37 PM
23	As commented above the school seem to be fighting us all the way despite the admission that little progress has been seen and that he needs the support. Health- I am still waiting for an very overdue appointment from the child development centre. He has not been reviewed since December 2018.	11/13/2019 6:41 PM
24	There are not enough speech therapists available so we get a reduced service.	11/13/2019 6:12 PM
25	The school is good at writing SEND Support plans, after our input has guided them to our son's needs. The delivery of the support is very often lacking. For Health, the GP and Asthma services have been good (particularly the asthma nurse) but the connection between the dentist and L&D has let us down.	11/13/2019 3:20 PM
26	I have no idea what do next to help my son. He does not need and EHCP but just good SEND support. We visited a different school and saw very good practise but remained as my son likes his Y4 teacher. I now regret this decision.	11/13/2019 3:07 PM
27	Education - Previous Central Beds Special School = Poorly (now in out of county School = very well) My child has a rare syndrome and very few specialist have even heard of, so it is a constant guessing game with her health but this is done via hospital consultants not Health in the EHCP	11/13/2019 10:55 AM
28	Due to the limitations in available subject teachers from either the school or Medical Services who can provide our daughter is behind on her other GCSE subjects and the lack of PHSE education has impacted her social development.	11/13/2019 9:53 AM
29	Neurodevelopmental conditions require multidisciplinary input. This is not the reality.	11/13/2019 9:42 AM
30	Currently in a very supportive school, however we have been refused a special school for starting year 7. We didn't make the decision lightheartedly and want the best for our daughter however we are being made to give her 2nd best and not what is in her best interests long term.	11/12/2019 7:42 PM
31	Due to a formal complaint to the CCG action is now being taken to identify myt daughters needs and engage with the right specialist staff ...its taken since 2016.	11/12/2019 7:23 PM
32	My son has recently started at an asd provision attached to a mainstream, he is on a phased timetable as he was out of school all of last half term. His last mainstream setting failed him and no one listened when I raised my concerns. A lot of damage has been done and I hope his new setting can support his needs.	11/12/2019 6:30 PM
33	The school do the absolute best they can, but my 5 year old needs a place in an autism unit (the type attached to a mainstream school). The one we want is full until Sept 2020 and if he doesn't get that place, there are no places until Sept 2021. He's needs the place today as he is on a reduced timetable and not accessing the curriculum properly. He is very bright and his potential will be wasted if CBC don't increase autism units. CBC need to look after these children NOW or they will be faced with massive bills for adult social care and mental health care for the children that they failed during their school years.	11/12/2019 1:26 PM
34	In social care there are simply no services, and Early Help seems to have no idea how to go about finding ways to meet unmet needs.	11/12/2019 1:23 PM
35	Until VERY recently his education needs were not met at all. He spent 2 years at Ardley Hill Autism Provision where he learnt virtually nothing despite being academically able. The school didn't even give him spellings or times tables to learn. They did not integrate him into mainstream or include him in school activities like plays, concerts etc. They did not safeguard him despite serious medical risks. The LA claimed NO responsibility because it is an Academy, despite us pointing out that the LA is ultimately responsible for ensuring provision within these children's EHCPs is met and that they commissioned and funding the unit. SEVEN out of nine parents removed their children from this provision due to their failures and abusive treatment, including forcing children into a cupboard and holding the door shut during autistic meltdowns. The LA conducted a safeguarding investigation but still takes no responsibility at all. We are awaiting an outcome from the Ombudsman. More recently he has moved to new autism provisions which meet his needs brilliantly - Ramsey Manor Lower and Arnold Academy Middle. However, the damage done by his 2 years at Ardley will take years to unpick.	11/12/2019 1:00 PM

Q13 As a parent carer how involved are you in setting targets and outcomes for your child/young person?

Answered: 155 Skipped: 1



	VERY INVOLVED	QUITE INVOLVED	NOT VERY INVOLVED	NO INVOLVEMENT	NOT APPLICABLE	TOTAL	WEIGHTED AVERAGE
Education	34.84% 54	37.42% 58	12.90% 20	13.55% 21	1.29% 2	155	2.09
Health	29.22% 45	27.92% 43	16.88% 26	11.04% 17	14.94% 23	154	2.55
Social Care	13.25% 20	12.58% 19	7.28% 11	11.26% 17	55.63% 84	151	3.83

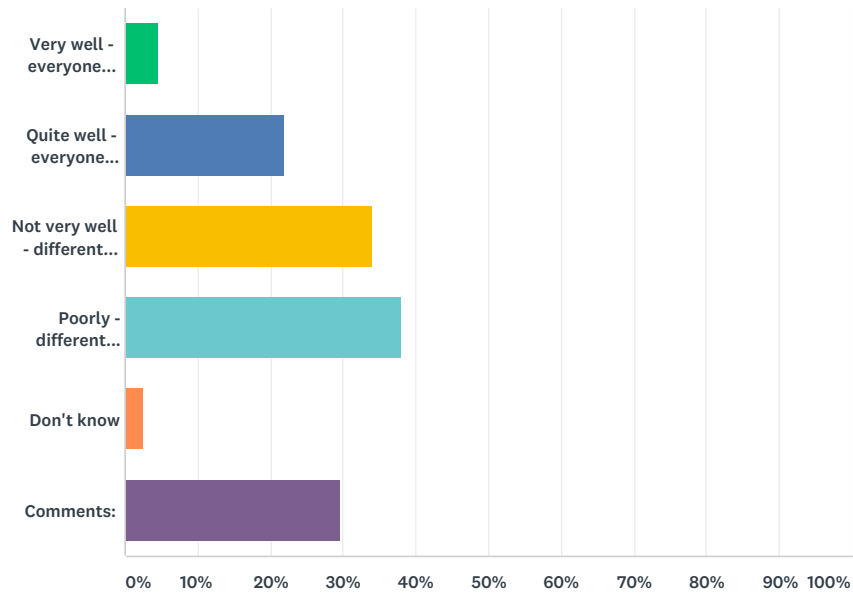
#	COMMENTS:	DATE
1	No support very little involvement. Again she masks so not issues seen in public or by others.	11/17/2019 4:36 PM
2	I am the main carer (not the parent) but there seems to be little communication between parent and school anyway. No communication regarding hospital admission and how is he now.	11/17/2019 2:17 PM
3	I am consulted. But as I'm not an expert it's hard to argue certain points about what he might benefit from more.	11/17/2019 1:23 PM

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4	On my own, as services and school are time consuming with lack of correct care and therapies and targets.	11/17/2019 1:22 PM
5	Our school no longer do iep's or reviews. There is no say unless you hound them which is never a good start.	11/17/2019 12:50 PM
6	Health and social care don't generally ask for opinions.	11/17/2019 12:37 PM
7	I am highly involved as I've had to fight every corner for my son. Writing letters to Ofsted, Department of Education, ESFA, Local Mp, Governors at Ardley Hill, and finally Ombudsman. When the system fails your child you have to take on the job of the SEND team. This has been the most stressful time of my life and my family due to these failures.	11/17/2019 12:04 PM
8	Target identified during annual review process but there is often no follow up after this on child's progress meeting or reviewing agreed targets until the next annual review. Health professionals do not seem even slightly involved in the EHCP. They do not provide long term outcomes even when I have requested them.	11/17/2019 11:53 AM
9	Not deemed as needing support as she does not have a learning disability or aggressive in class.	11/17/2019 4:32 AM
10	School do not like any questioning by parents of the outcomes on the SEND support plan	11/16/2019 11:13 PM
11	See above	11/16/2019 10:25 PM
12	School parent interested as she doesn't bring them money and she masks at school so her issues are forgotten	11/16/2019 10:16 PM
13	Until I bring it up with them, I don't think my son's social care setting is aware of, or considers, the outcomes in his EHCP. I have been asked many times by care providers what my aspirations are for my son, when its all there in his EHCP if they would only look at it. In my experience, health professionals have no knowledge of what an EHCP is and would likely not consider its contents particularly relevant to their medical treatment decisions anyway even if they had time to look at its contents.	11/16/2019 7:19 PM
14	My child is now home educated so I have answered regarding his previous recent education setting.	11/16/2019 7:09 PM
15	Due to changed that is going to happen	11/16/2019 3:35 PM
16	Health have no suitable criteria for a child who is not physically disabled, therefore, they do not accurately measure my son's health needs.	11/16/2019 3:28 PM
17	Targets are set by school but are not carried out as state lack of staff or resources not produced. When questioned 'We don't feel it was needed in end or there isn't enough staff- he managed without'	11/16/2019 10:16 AM
18	I have taken a reduce my hours at work, to support my son, in getting the right support. This has included constant meetings, reviews, phone calls, mediation, appointments, setting targets, amending the ehcp plan. We have also spent money commissioning private reports as the reports from ep has not been good enough.	11/13/2019 11:38 PM
19	School rarely set outcomes or targets for the needs of my child. When this does happen i am involved. School only meet with me regarding my childs needs when I request to do so.	11/13/2019 8:26 PM
20	We are very involved but it seems very little gets implemented.	11/13/2019 3:07 PM
21	Education - Previous Central Beds Special School - under new leadership = No involvement - were not interesting in individual outcomes just bulk learning. Now at new school -Quite Involved	11/13/2019 10:55 AM
22	We are having to drive some of the professionals to ensure they are providing the necessary resources and support for our daughter needs.	11/13/2019 9:53 AM
23	We try to be. However, information regarding what is available to our child is not forthcoming or easy to find. We rely heavily on other parents' knowledge and fighting for care that simply isn't available; but very necessary.	11/13/2019 9:42 AM
24	Constant monitoring of professionals is needed to ensure SMART targets are met - initial APDR provided by upper school was poor ..sentences such as " access to" no specifics , staff wanting to rush me through the APDR , requiring me to constantly revisit each point to make it SMART. Despite having thr plan in place it's not followed consistently by staff. Staff have a poor understanding of my daughter's needs. We had been discharged from all health services , no support , commissioned SALT and OT services are inadequate and do not meet the needs of children with ASD who just present with sensory processing difficulties or have SCLN consistent only with ASD. Conflicting views on PDA between paediatric neurodevelopmental team and CAMHS - this needs addressing for the county, particularly as a demand avoidant profile is mentioned in NICE cg170 .	11/12/2019 7:23 PM
25	I have to be strongly involved as I no longer trust anyone to set them and work towards achieving them properly.	11/12/2019 6:30 PM
26	The school involve us fully. Central Beds don't have the provision available to meet our son's needs though.	11/12/2019 1:26 PM
27	Only because if we weren't VERY involved, nothing would happen. We have to drive and badger for everything.	11/12/2019 1:23 PM
28	Ardley Hill autism provision didn't even bother to review EHCPs unless you hassled them for months on end. The LA didn't prompt them to do it as they were snowed under with changing statements to EHCPs. We haven't reviewed yet at his new school so I can only comment on the last 2 years' experiences.	11/12/2019 1:00 PM

Q14 How well do you think services and professionals work together to support your child/young person?

Answered: 155 Skipped: 1



ANSWER CHOICES	RESPONSES
Very well - everyone involved with my child/young person communicates well and makes decisions together	4.52% 7
Quite well - everyone communicates and works together most of the time	21.94% 34
Not very well - different professionals and services sometimes communicate and work together	34.19% 53
Poorly - different professionals and services rarely or never communicate and work together	38.06% 59
Don't know	2.58% 4
Comments:	29.68% 46
Total Respondents: 155	

#	COMMENTS:	DATE
1	Don't believe they do. Too stretched and they don't see a need because she masks.	11/17/2019 4:36 PM
2	One Team Around the Child meeting has not filled the parent with confidence. In secondary school, about 2 years ago, the meeting involved the specialist Nurse, the School Attendance Officer and CBC's SAO/EWO. That was it. Poor show. Did not demonstrate what could have helped the child. (Parent being told to get the child to school, parent trying to get to the bottom of school refusal, no suggestions as to what had happened to the child, what would help the child, e.g. different way of learning, different setting). Consultant thinks child has burn-out dealing with his medical condition and an underlying learning difference.	11/17/2019 2:17 PM
3	School do not take on medical advice	11/17/2019 1:42 PM
4	We haven't had experience if that yet. Only gatekeeping	11/17/2019 1:23 PM
5	Different and or same professionals communicate but it's the opinions that are always wrong and I have proven right difficulties my son has by independent spectrum specialists.	11/17/2019 1:22 PM
6	Cdc have asked school repeatedly to get the Asd advisory in. Taken three years, only just got the consent form for them to go in!	11/17/2019 12:50 PM
7	They never seem to have a clue what the other have suggested or why. No one attends annual reviews although invited. Always just the class teacher.	11/17/2019 12:37 PM
8	It's easier to write emails and copy everyone in, because they fail to communicate with each other. CBC failed to chase up EHCP's!	11/17/2019 12:04 PM
9	Central beds SEN team at do not listen to the views of my child's school when making decisions. Health professionals only Rarely seem to communicate and information only shared by reading the last clinic report. Often have to repeat information about my child repeatedly to each health professional we see. Ensure professionals are well trained and understand the EHCP process and their part in it and make them accountable for following procedure properly as per SEN code of conduct.	11/17/2019 11:53 AM
10	Never have multidisciplinary meetings	11/17/2019 9:14 AM

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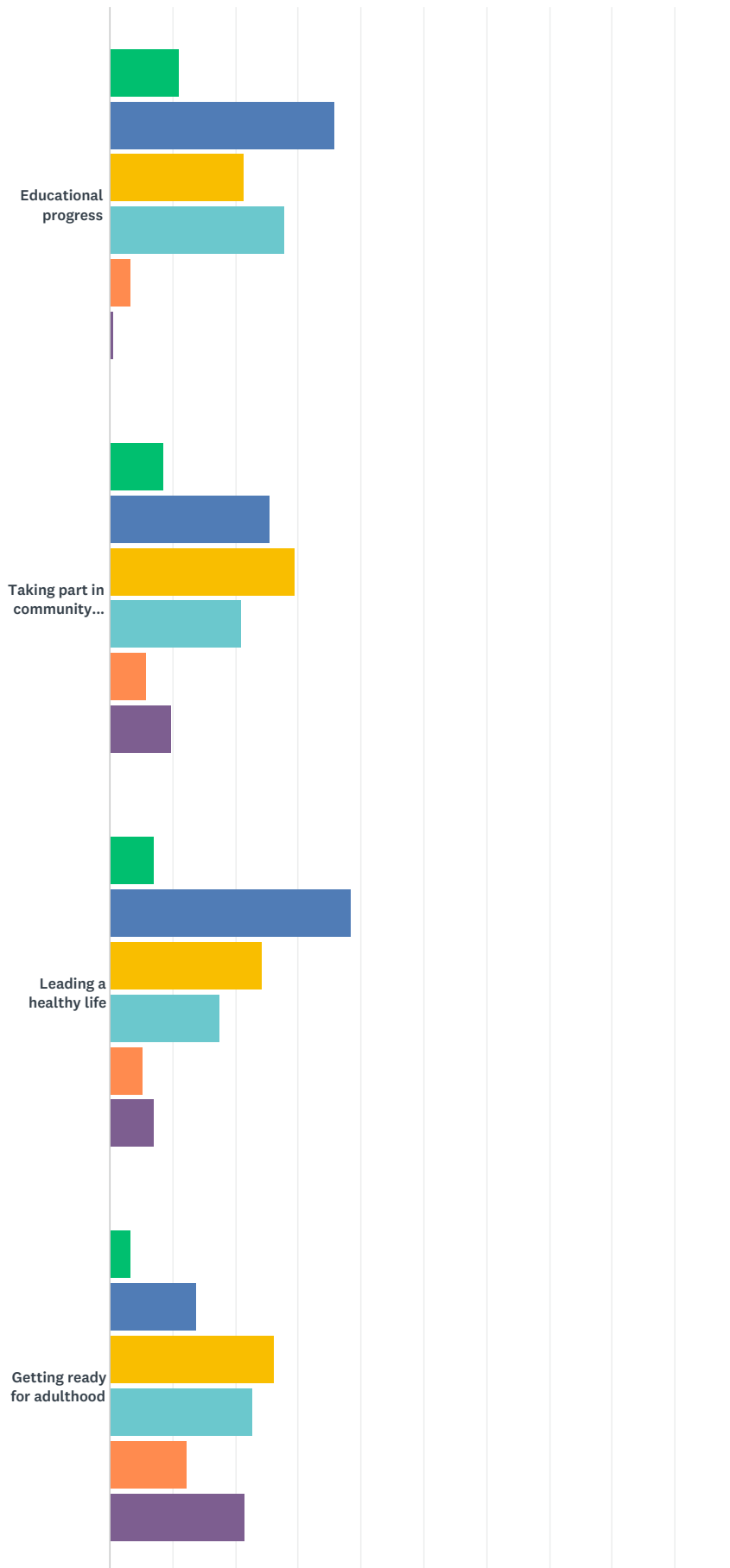
11	9		11/17/2019 8:07 AM
12		CAMHS visited one class teacher 3 years ago. CDC didn't even send diagnosis letter to school No advice given to school for girls with autism No understanding/recognition of spd Huge waiting time to access CDC	11/17/2019 4:32 AM
13		The parent absolutely has to act as the linchpin and keep on top of everything	11/16/2019 10:54 PM
14		It's a blame game. Everyone tells you to seek another service and the services do not talk	11/16/2019 10:27 PM
15		There are no outside professionals working with my daughter (except the private ones I pay for). Even between teachers and SENCo within school there seems to be a lack of communication and cooperation.	11/16/2019 10:25 PM
16		CAMHS have attended reviews and communicated with the new placement. Previous SENCo did try to liaise with SEND on SALT and OT needs but was met with obfuscation and misleading info. as was I. We have not had a review in the new placement yet, so I can't comment on that, but so far they seem proactive. I have just been asked by the SENCo to complete a parent/carer needs assessment, but as yet can't comment on SW input.	11/16/2019 8:39 PM
17		There is some link-up between educational and social care. But I have never seen any evidence that college staff or social workers communicate with any NHS consultants that treat my son.	11/16/2019 7:19 PM
18		Health is very good st communicating to education. Communication from education services and SEND department is awful.	11/16/2019 7:09 PM
19		Senco in my sons school ignores his needs	11/16/2019 6:57 PM
20		only in terms of education. No other parties are working on/for him	11/16/2019 6:36 PM
21		Please can schools listen to Edwin Lobo reports and follow their specialist advice	11/16/2019 6:21 PM
22		I only have school support at the moment and they aren't really interested in getting my son diagnosed	11/16/2019 5:46 PM
23		V poor communication between parties.	11/16/2019 3:28 PM
24		Massive failings in early years -health, social/emotionally, nursery unprepared and ongoing through school for him and family	11/16/2019 12:14 PM
25		School do not follow advice given by specialists such as paediatrician, OT, physio. There is very specific advice but school do not have the time/staff. I feel the school has to pick up on all advice but the individual service discharge back to the school when the physio/OT should carry out their specialist interventions. They not work cohesively due to separate budgets.	11/16/2019 10:16 AM
26		.	11/14/2019 8:57 PM
27		Unfortunately none of the professionals work together. CBC and healthcare sector do not work together, they do not attend panel meetings to review the needs assessment to ensure the right health care support is in the plan. Most members salt, paediatrician do not know how to write provisions and outcomes for the EHCP Services within the council do not work together this includes the eyst team, we had 3 different members of staff, but each time we had to explain where the support was needed.	11/13/2019 11:38 PM
28		They never turn up to TAC meeting	11/13/2019 8:57 PM
29		As we are on the beds/bucks border our gp and camhs are in bucks we live and the children go to school in Bedfordshire. I have no idea if school has had any contact with other professionals about my children. They have offered workshops for anxiety which were well received by my children.	11/13/2019 8:26 PM
30		Teams within social services have been ery difficult to talk with one another. The finance team were awful, no emails answered from us OR social worker!	11/13/2019 7:49 PM
31		We are split across Leighton Buzzard which means services cross Counties and no one communicates.	11/13/2019 7:37 PM
32		A plan was put in place by the council when starting school by Sally Pratt who assessed our son and the school havent follwed this. We are paying for a private assessment of our own.	11/13/2019 7:33 PM
33		Only one occasion have they contacted each other in 4 years.	11/13/2019 6:41 PM
34		He doesn't need lots of different services, just good SEND support	11/13/2019 3:07 PM
35		School and health don't complete each other's questionnaire	11/13/2019 12:40 PM
36		Our Ehcplan was done 4 years ago, it doesn't give a true reflection of what's needed now but the few lines that are added each year don't add up properly for his needs. Our latest one was submitted in July and we've heard nothing since and nor have the school	11/13/2019 12:08 PM
37		All professionals around my son are saying he needs special needs provisoin but the SEND team have made the decision that he does not. All education and health professionals are working very well together - it is the SEND team that are working by themsleves to a different plan that NO other professional agrees with.	11/13/2019 11:39 AM
38		Old Central Beds School under new leadership would not communicate or work with social care or parents ~social care were excellent	11/13/2019 10:55 AM
39		It has taken continued effort and drive by ourselves to get multi / cross agency engagement and co-ordination.	11/13/2019 9:53 AM
40		There is no cross-service communication	11/13/2019 9:42 AM
41		For the EHCP assessment I had to chase different professionals due to communication problems between the LA and certain services	11/13/2019 9:33 AM

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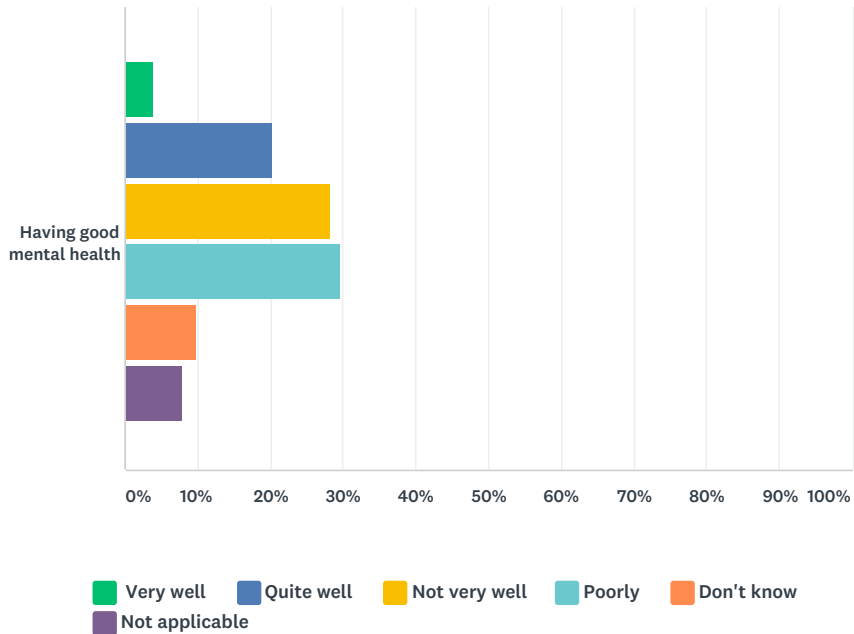
42	This has improved since a formal complaint was made to the CCG.	11/12/2019 7:23 PM
43	Services are disjointed, I am constantly having to repeat my sons needs to each service. No one takes responsibility or accountability.	11/12/2019 6:30 PM
44	The school works well with other agencies, but involving CBC is hard. They don't communicate at all. At times it's taken 2 weeks of both myself and our SENCO trying to contact CBC for a simple answer about something. Staff turnover in the SEND office has been high, so no-one even knows what they're doing, there's no continuity and no expertise.	11/12/2019 1:26 PM
45	I despair of how poorly we are supported. My daughter has been out of school for four years!! Medical Needs won't adjust their approach to meet my daughters ASD needs so now won't teach her. Shocking position to be in.	11/12/2019 1:22 PM
46	I have 2 autistic children and it is a full time job doing all their paperwork and filling the gaps and communication failures between education, health and particularly the LA. Getting any kind of response from the SEND office takes days of emailing and phoning. Emails aren't answered and if you call, they are eternally 'away from their desk'. It is a constant headache.	11/12/2019 1:00 PM

Q15 Overall how well do the services your child/young person uses help them to reach their potential?

Answered: 154 Skipped: 2



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	VERY WELL	QUITE WELL	NOT VERY WELL	POORLY	DON'T KNOW	NOT APPLICABLE	TOTAL	WEIGHTED AVERAGE
Educational progress	11.04% 17	35.71% 55	21.43% 33	27.92% 43	3.25% 5	0.65% 1	154	2.76
Taking part in community activities	8.50% 13	25.49% 39	29.41% 45	20.92% 32	5.88% 9	9.80% 15	153	2.89
Leading a healthy life	7.19% 11	38.56% 59	24.18% 37	17.65% 27	5.23% 8	7.19% 11	153	2.73
Getting ready for adulthood	3.27% 5	13.73% 21	26.14% 40	22.88% 35	12.42% 19	21.57% 33	153	3.35
Having good mental health	3.95% 6	20.39% 31	28.29% 43	29.61% 45	9.87% 15	7.89% 12	152	3.23

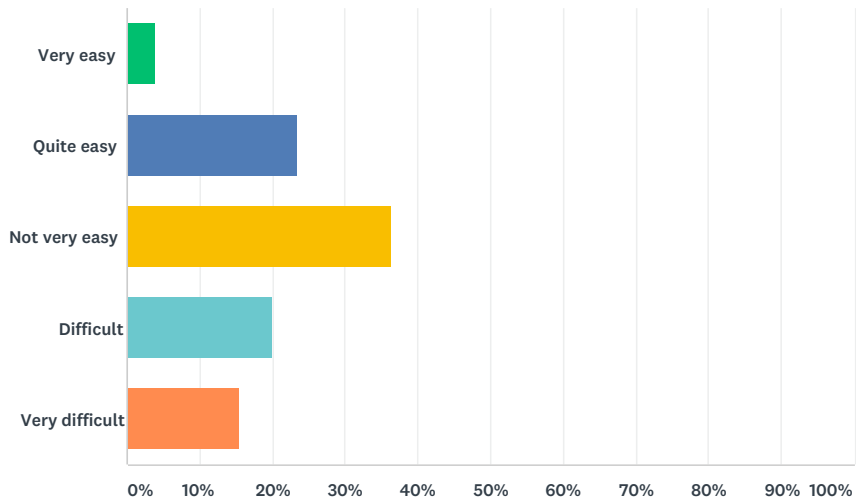
#	COMMENTS:	DATE
1	Little to nothing offered. All found privately or via snap.	11/17/2019 4:36 PM
2	Child attends youth club paid for by CBC and local council. Child loves the range of activities available and enjoys the company of the adults and his peers.	11/17/2019 2:17 PM
3	Camhs Dunstable dr chowdhury brilliant	11/17/2019 1:42 PM
4	Services cherry pick and always pick children under care and Camhs only!	11/17/2019 1:22 PM
5	Little to no support as she doesn't pose a problem to any yet.	11/17/2019 12:50 PM
6	Social care have provided direct payments this has increased my sons independence. Lack of health appointments leaves us not knowing whether certain health issues like epilepsy are an issue or whether it's something else? Education I am unsure that my son is in the correct class at school. But no discussion takes place. It's a we know best.	11/17/2019 12:37 PM
7	Please read other comments.	11/17/2019 12:04 PM
8	Mental health services for YP in crisis. Long waiting lists, lack of therapy interventions. My child assesses quite a few community activities, scouts, autism beds youth club etc which are fabulous but their is a need for more inclusive activities and clubs outside of school that YP with SEN can access. We had to wait for a year on the waiting list for the autism beds youth club. Funding should be provided to allow more children to access as these clubs are invaluable to intergrating our children into communities and providing independence and skills for their adult life. It is good to see that Central beds have started putting on some school holiday activities for children with SEN just recently. It would be good to see this developed further in the future.	11/17/2019 11:53 AM
9	As parents we corordinate all his care and are the driving force in providing therapies. A lot of which have to be privately funded due to lack of support from government, educational budgets.	11/17/2019 8:38 AM
10	Can't get support she needs as not aggressive in school and is capable educationally. Very aggressive and emotionally challenging as soon as she gets home.	11/17/2019 4:32 AM
11	At the moment nothing has done to fruition enough	11/16/2019 10:54 PM
12	It concerns me that due to the lack of understanding, expectations will be lowered and that her self esteem will be affected.	11/16/2019 10:25 PM
13	My daughter suffers with anxiety and at the age of 10 now calls herself ugly and fat. Her perception of herself is low due do mental health	11/16/2019 10:16 PM
14	Our sons difficulties mean that is is almost impossible to access services outside of school. Within school his involvement is limited by his complex needs.	11/16/2019 8:39 PM

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15	Community activities currently accessed are those we organise as a family. We are bedn unable to access those organised by the LA as not enough information has been given about them in advance, for example more specific detail on activity, how many other people will be there (how busy it is) or due to time and cost (having more than one child and having to give up work to educate one of them due to theAs failings has meant we have to keep a close eye on spending.	11/16/2019 7:09 PM
16	My sons mental health is ignored outside the school	11/16/2019 6:57 PM
17	Because I make sure they do	11/16/2019 3:35 PM
18	Only because my son is in a waking day curriculum school out of county that he receives suitable care and education. When he was in county, the social care and education were dire. This was confirmed by the judge after going to tribunal as the judge said it was beyond belief how incompetent the LA were.	11/16/2019 3:28 PM
19	Mental health services non existent when needed.	11/16/2019 12:14 PM
20	I strongly feel that because my child does not have a very apparent or disruptive SEN, they are swept under the carpet At school due to the lack of resources. They do not have their social or emotional needs considered or met impacting on their mental health and making them a target for bullying. As a parent every resource you try to access is a battle.	11/16/2019 10:16 AM
21	Lack of support means my child is failing. My daughter has a diagnosis and lost her funding for full time support when she turned 3! A disability does not vanish a month after your birthday? Her disability is for life.	11/13/2019 7:37 PM
22	We access Autism in Bedfordshire And Kids in Action Children's Charity	11/13/2019 4:44 PM
23	We don't use many CBC community activities but our son is a Cub Scout and plays at his local tennis club.	11/13/2019 3:20 PM
24	There are few services that work with community social interaction. My child is socially isolated much of the time	11/13/2019 12:40 PM
25	Found Chums terrible to use, ages to get on a list only to be told it was anxiety due to autism-off the list My other twin they couldn't be bothered to recontact me on the day I missed a call running to my phone even though we supposedly had at least a half hour slot	11/13/2019 12:08 PM
26	The schools are helping Ben reach his potential educationally and helping wiht mental heath but we are awaiting servies to support his mental health. He does not take part in community activities as the majority of special needs services are physical - forest school activities, trampolining, swimming. The only one really is the cinema and that is not supporting a healthy lifestyle.	11/13/2019 11:39 AM
27	Our son has struggled with his perception of himself despite requests from our GP, Us, School and his paediatrician we are yet to see anyone from CHUMS or CAMHS.	11/13/2019 11:00 AM
28	Our daughter is unable to cross educational physical boundaries and requires focused 1:1 education. We need to ensure that she has 25 hrs teaching available to her whilst recognising there will be days and even certain hours where she will not be able to attend / complete / focus on particular sessions.	11/13/2019 9:53 AM
29	Parents are required to push for any services to meet their childs needs, which further impacts the family dynamic and their wellbeing.	11/12/2019 7:23 PM
30	My sons experience has caused so much damage, he has regressed in all areas and now had mental health needs.	11/12/2019 6:30 PM
31	There is not enough information to seek help on younger children who are suffering from anxiety. My son is 4 has ASD and is suffering from trouble anxiety and I feel we are struggling for some help & guidance.	11/12/2019 4:10 PM
32	My daughter only accessed the community via local charities (Mencap and BDCPS) who run holiday and Saturday activities which are good for her, however I know that they aren't completely funded by the local authority.	11/12/2019 1:58 PM
33	This is only because of a out of county provision.	11/12/2019 1:35 PM
34	He won't reach his potential in his mainstream school, even though it is a brilliant school that does everything they can for him. He needs to be in a mainstream autism unit, but there is ONE space for Sept 2020 and dozens of families that need it. It all just feels futile.	11/12/2019 1:26 PM
35	If it wasn't for CAMHS we would have no help or support at all	11/12/2019 1:22 PM
36	I have answered this question in relation to my son's 2 years at Ardley Hill Autism provision, as he hasn't been at his new provision long enough to judge this well. Ardley Hill Autism provision failed him in every way and damaged his mental health, which had previously been fine. Being repeatedly locked in a cupboard when at their most vulnerable, by the staff who were meant to be nurturing them has had that affect on all children who attended the provision.	11/12/2019 1:00 PM

Q16 How easy do you find it to get information about what services are available and what they do?

Answered: 154 Skipped: 2



ANSWER CHOICES	RESPONSES	
Very easy	3.90%	6
Quite easy	23.38%	36
Not very easy	36.36%	56
Difficult	20.13%	31
Very difficult	15.58%	24
TOTAL		154

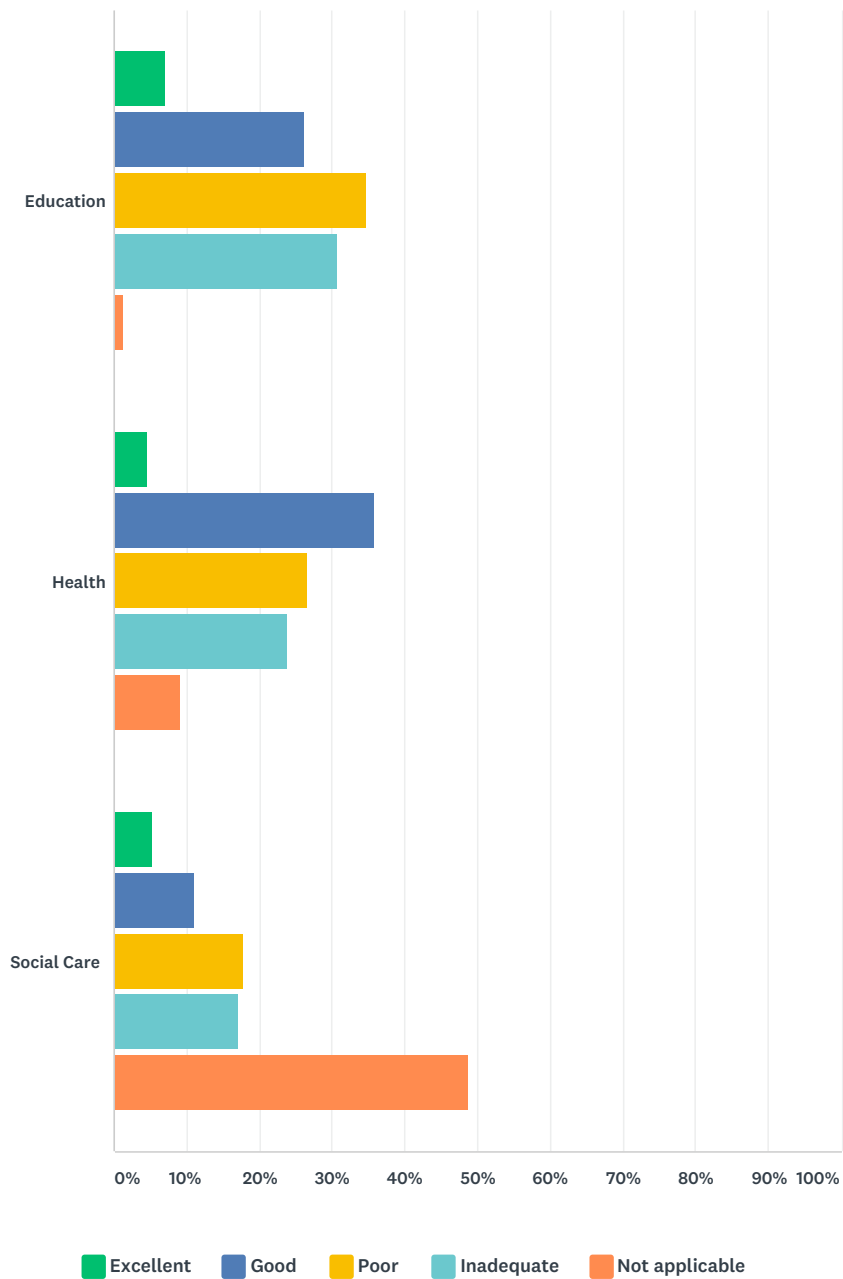
#	COMMENTS:	DATE
1	Only via snap	11/17/2019 4:36 PM
2	It would help if the child was in school more often. He is anxious about things that as a carer, I cannot pinpoint. Would be good to for school to keep in touch with him in a "how are you? we have this happening, would you like to join us?" way. It is brilliant that the youth club does visit school.	11/17/2019 2:17 PM
3	I get most I formation from SNAP	11/17/2019 1:23 PM
4	Only through snap etc.	11/17/2019 12:50 PM
5	Most information comes from other parents, parent forum calendar.	11/17/2019 12:37 PM
6	Find SNAP parent carer forum information and the information from Autism Beds really informative about what's going in in the local area. Use their emailed newsletters, websites, advice lines and social media updates to find out about local SEN information, parent carer training and SEN activities available locally. Schools have got better about communicating with parents about local SEN services and information which is positive.	11/17/2019 11:53 AM
7	It would help to just have one list to consult To see where can access assistance from. Have to ferret around a lot to find info	11/16/2019 10:54 PM
8	The local offer is dreadful. It only signposts to organisations I know about.	11/16/2019 10:25 PM
9	Communitywise, we have tried LOAF which is aimed at children with an ASD diagnosis, but this wasn't appropriate for a child as active and anxious as ours. We tried the local SEN/disability swimming group, but it did not work for our anxious child as behaviour from other children was often unpredictable and very loud. We also tried various mainstream activities such as climbing, soft play centres, gymnastics, but our son was not able to engage appropriately in a consistent way. The only place we have used successfully is FUN in Luton which holds sessions for children with ASD during the holidays which we can access, although it is quite far away.	11/16/2019 8:39 PM
10	I can rarely find what I am looking for on the local offer. Most information about services I get from other parents	11/16/2019 7:19 PM
11	Information about services is good, as long as you know where to look, services, eg education settings are not forthcoming in pointing parents towards the local offer. Access to many services is restricted to education settings (who in my experience are very reluctant to refer) or GPS, who seem to want schools to refer.	11/16/2019 7:09 PM
12	Once diagnosed with ASD, they was nothing. I was told about things through friends	11/16/2019 7:00 PM

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13	I get most of my info from the local offer which I only found out about via SNAP PCF	11/16/2019 6:36 PM
14	I have no idea what services are available, where or when they are	11/16/2019 6:31 PM
15	There is nothing available for my daughter in central Bedfordshire, there is once a term stay and play in toddington which is too far out to me. I'm not happy that my daughter has no access to anything deaf related	11/16/2019 6:26 PM
16	Though other people	11/16/2019 3:35 PM
17	This is from SNAP The website for CBC is very difficult to find information, including the local offer. The send team themselves do not offer any advice or support, you can hardly get hold of them, they do not advise you on ehcp support. Most preschools do not understand who they should contact regarding referrals including 2 we attended. They did not know where to direct us to support before diagnosis. We spend 2 years with no support.	11/13/2019 11:38 PM
18	It hasn't been easy for the past two years but since I attended Autism Bedfordshire Childrens Conference i have met other great organisations like SNAP. I finally dont feel so alone!	11/13/2019 9:43 PM
19	I find it difficult to find information about services for my children on the spectrum and adhd. I dont know what services they can access through school. I would like more info on youth clubs and counselling services. Anything i have seen that may benefit us is in school hours which is unsuitable for us as i work fulltime. Having some drop in sessions or more information courses/workshops in the evenings and in the Dunstable area would be beneficial. Also some workshops are only available to those diagnosed in Bedfordshire, as we live on the border (still in Bedfordshire) with Buckinghamshire my boys were diagnosed in Buckinghamshire. It would be helpful to allow these livibg in Bedfordshire to access these workshops.	11/13/2019 8:26 PM
20	Parent power is the best form of information	11/13/2019 4:44 PM
21	It's like being a detective just to find out what you should be entitled to, then being a boxer on a length of elastic as u have to fight for every little thing and go back and forth with emails, phone calls and eventually threaten solicitors just to get what ur children are entitled to-and they worry about their mental health, it's exhausting and I've had to give up most of my work just to negotiate the pathway- it's just not right and really unjust	11/13/2019 12:08 PM
22	The local offer page with the support of SNAPP has been updated well.	11/13/2019 11:00 AM
23	Until I found SNAP PCF I had struggled to find any information However, SNAP has now been my main source of information as they are very useful	11/13/2019 10:55 AM
24	We have heard of an Alternate Provider list which the Council has but as yet have not seen it despite asking both verbally and in writing.	11/13/2019 9:53 AM
25	I have access to social media so it's easier to find what services are available through this but I have had to look for these myself. It isn't always clear.	11/13/2019 9:33 AM
26	Unless I was familiar with the systems due to.my professional experience I would not have got this far.	11/12/2019 7:23 PM
27	I have knowledge of how to navigate the services available but this would be difficult if I did not have prior knowledge	11/12/2019 6:30 PM
28	Feel like there needs to be more information given out. Through social media or email.	11/12/2019 4:10 PM
29	I only find out about stuff from other parents	11/12/2019 1:58 PM
30	Quite easy because I get it from other parents and from Googling! The CBC website doesn't have enough information. Real-life info from other families is far more valuable than anything you will find on the Local Offer.	11/12/2019 1:26 PM
31	The local offer is hard to navigate and didn't provide enough information (until a couple of weeks ago when the LA suddenly added a shed-load of information because they knew their CQC/Ofsted inspection was due)! Google is a far more useful resource than the Local Offer, as are other parents who are already in the system.	11/12/2019 1:00 PM
32	The local offer website is work in progress	11/12/2019 11:33 AM

Q17 How would you rate the provision provided locally?

Answered: 153 Skipped: 3



	EXCELLENT	GOOD	POOR	INADEQUATE	NOT APPLICABLE	TOTAL	WEIGHTED AVERAGE
Education	7.19%	26.14%	34.64%	30.72%	1.31%	153	2.90
Health	4.64%	35.76%	26.49%	23.84%	9.27%	151	2.77
Social Care	5.26%	11.18%	17.76%	17.11%	48.68%	152	2.91

#	COMMENTS:	DATE
1	There is nothing out there for high functioning autistic girls who mask.	11/17/2019 4:36 PM
2	How can Alternative Provision, one day a week, off-site, be a "Reward"? It seemed to suit the child better. Removed as he cannot cope going in to school.	11/17/2019 2:17 PM
3	Little to none. All through snap.	11/17/2019 12:50 PM
4	Social care cuts and downgrading and taking away packages that children have had for many years is happening. Health, no appointments! Education, buildings poor and poor staffing.	11/17/2019 12:37 PM
5	Absolute disgrace!	11/17/2019 12:04 PM

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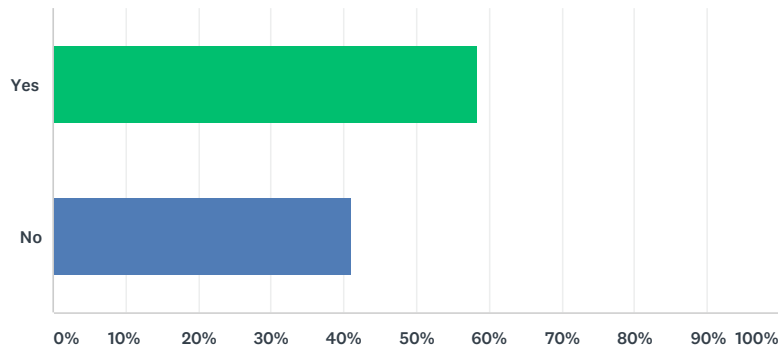
6	Central beds have made an effort to provide parent carer training on EHCP's and annual reviews which is positive, although not always at convenient times for working parents but unfortunately in practice they often don't follow what is taught in their training courses, eg review EHCP in agreed timescales, obtain updated assessment and advice from professionals in time for annual review meetings etc.. what is supposed to happen often does not. There are not enough school places in mainstream SEN units and special schools which means those that are available are over subscribed and overstretched. You have to go to Tribunal to get a place at the good schools and children often then have to travel a fair distance to school each day to access their education.	11/17/2019 11:53 AM
7	There are a small amount of special schools who are massively oversubscribed. Those children that might not fit the mould for special school or mainstream are let down. You can never get hold of anyone at the council SEND team and I feel they are letting children down.	11/17/2019 8:38 AM
8	Barriers to services due to no ehcp. Entitled to very few avenues of support. Local offer during holidays isn't geared up for children with autism. No respite. Only respite is through autism Beds run summer scheme and loaf.	11/17/2019 4:32 AM
9	Other local authorities have SpLD bases and teachers - CBC don't have anything like this. I don't think she needs someone to work individually with her (although it would have been very good if we hadn't needed to pay £350 for an assessment). I do think schools need more advice, training and support.	11/16/2019 10:25 PM
10	Not offered help due to not being severe enough, issues are masked in public and I'm not believed even with videos etc to show I'm not lying	11/16/2019 10:16 PM
11	We receive direct payments for a carer to support us in the home allowing us to access the community as a family to a greater degree. It also allows the sibling of our child with disabilities to have time with his parent/s while his brother with SEN has time with his carer.	11/16/2019 9:47 PM
12	There are only 2 school units in Bedfordshire where our son's mental health needs could be met, but only one is a lower school (he is 5). The journey time is 45 minutes minimum each way. It could of course be worse. The problem I am concerned about is the social aspect. Our son's previous school was just around the corner and he went to all the birthday parties, had play dates etc. Now the opportunities to continue friendships outside school are practically nil, since we are so far away, but also the other children the unit may be 45 minutes away in the opposite direction. Edwin Lobo have consistently been excellent and although we have only had 2 face-to-face appointments, we have had telephone discussions and been helped by the PA to Dr Omisakin. This has met our needs and I have been very happy with what they could offer, particularly given their workload. I don't think I need to comment further on the lack of SALT input and the nonexistent OT provision for sensory needs in Bedfordshire.	11/16/2019 8:39 PM
13	Long waiting lists and long time to make referrals despite parents raising concerns	11/16/2019 6:21 PM
14	Very poor. This is why my son has to attend school out of county. Provision in Central Beds is inadequate.	11/16/2019 3:28 PM
15	Edwin Lobo are fantastic and very thorough but the waiting lists are enormous. Schools are stretched and unwilling to use their budget. I feel early intervention is essential but is being delayed for years or until a child hits crisis point	11/16/2019 10:16 AM
16	Education - There is not enough ASD provisions or specialist schools. Mainstream schools are at breaking point as most cannot support the children and do not have enough resources in their sen budget to meet the needs. There is hardly any qualified staff that understand autism Health - not enough specialist salt professionals, no sensory integration OT trained professionals. Diagnosis process is too long, not enough paediatricians	11/13/2019 11:38 PM
17	The Chiltern school needs a whole new leadership team	11/13/2019 7:41 PM
18	No respite centres and hard to access	11/13/2019 7:23 PM
19	Most services are the other side of the county or in Bedford borough. There are NO speech & language units post lower school in the county. No specific MLD only school this side of county, the nearest one is Bedford borough but we wouldn't qualify for transport to get there.	11/13/2019 6:12 PM
20	Our two older sons are high achievers at school. This 'poor' rating is purely connected to SEND Support	11/13/2019 3:20 PM
21	Our school hasn't had an OFSTED inspection since 2007. There have been high levels of spending on school aesthetics and I question whether this affected SEND provision. The school does provide a 'Koala Club' which I feel is successful and some of the staff are extremely supportive with my son's needs. I have challenged the school about the provision and feel nothing has changed. This has been ongoing for 3 years and I am on the brink of giving up. I look forward to middle school.	11/13/2019 3:07 PM
22	Education haven't the know how or money in the pot Health don't even recognise sensory otherwise they'd have to fund... Shall I go on, it's inadequate in every way and one day in the not so distant future they're going to be paying huge sums of money to the children let down by this system and the law firms making a living because of it	11/13/2019 12:08 PM
23	Very little extra curricular activities offered to young people with needs such as sports groups.	11/13/2019 11:00 AM
24	We need to state that this is not a criticism of Medical Services who have been fighting with us to get the right level of care and support. Our challenge has been with CBC, specifically the SEND team, in getting engagement, responsibility and action	11/13/2019 9:53 AM
25	Lack of SALT and SI OT services for children with ASD profile who do not have functional or SCLN that are consistent with ASD profile. Lack of expertise in CaMHs tier 1 and 2 services (CHUMs) to identify revolving door referrals into the service. Inadequate funding at this level to meet needs appropriately .	11/12/2019 7:23 PM

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26	My daughter is in a Bedford Borough Special School as the Central Beds schools couldn't meet her needs	11/12/2019 1:58 PM
27	Education seems ok in central beds unless your child has pmlid severe autism and very challenging behaviour, then it seems a massive battle due in my opinion down to cost	11/12/2019 1:35 PM
28	I have a small circle of SEND friends. I know 5 children who need places in mainstream autism units. Two of them have been forced to homeschool because their child can't cope with mainstream. I have a two friends whose children were at home for a YEARA after removing them from the Ardley Hill unit as there were no spaces available anywhere else and Ardley was treating the children badly.	11/12/2019 1:26 PM
29	DEEPLY inadequate. All specials schools are bursting at the seams, particularly Weatherfield. There is no-where near enough provision for autistic children who are academically-able, but unable to cope in mainstream. Education - The unmitigated failure of Ardley Hill Autism Provision has had a knock on effect to the availability of spaces in the other (very limited) autism provisions across the county. They are all full and MANY children are being forced to home educate because appropriate autism provision places are not available. I fear the LA do not count these children when (if) they are planning future SEND provision places. Health - You have to wait an age to see CAMHS and Edwin Lobo.	11/12/2019 1:00 PM

Q18 Have you heard of the 0-25 Central Bedfordshire SEN & Disability Local Offer?

Answered: 154 Skipped: 2

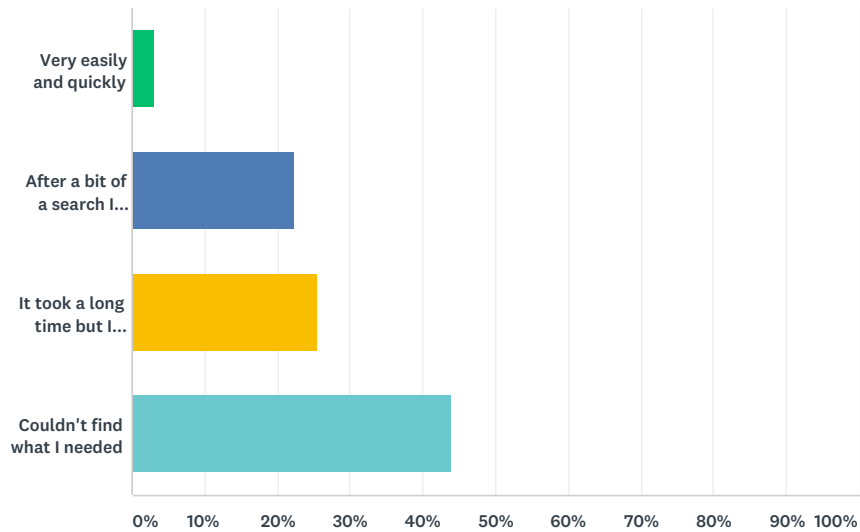


ANSWER CHOICES	RESPONSES	
Yes	58.44%	90
No	40.91%	63
TOTAL		154

#	COMMENTS:	DATE
1	I looked within the last two weeks. All I found was a government leaflet. Could not see alternative ideas to mainstream education.	11/17/2019 2:17 PM
2	Only because I was art if a foul is group with snap.	11/17/2019 12:50 PM
3	Looked for Young carers information. Disappointed to find out nothing is on offer.	11/17/2019 12:37 PM
4	Only because they came to loaf the other week to ask our opinions on their website. We expressed our dissatisfaction about inclusivity at their holiday activities.	11/17/2019 4:32 AM
5	It offers nothing for families where children aren't eligible for EHCP.	11/16/2019 10:25 PM
6	My daughter NEEDS more support in school as much as ANY child with sen needs, just because she masks doesn't mean she is any less deserving.	11/16/2019 10:16 PM
7	Confusing, not user friendly.	11/16/2019 8:39 PM
8	via SNAP	11/16/2019 6:36 PM
9	Pure rhetoric.	11/16/2019 3:28 PM
10	I don't know if I have or haven't. The wording for all the different things is very confusing	11/16/2019 3:14 PM
11	Was given it this week.	11/15/2019 7:47 PM
12	I have called them but no real help was provided.	11/13/2019 7:37 PM
13	Because I work in SEN.	11/13/2019 6:41 PM
14	Because I searched for help.	11/13/2019 1:18 PM
15	Why did it change in April 2019? Before that date everyone was to have their own case worker.	11/13/2019 12:11 PM
16	Only after I joined SNAP PCF, I heard about the Local Offer, although it is a minefield to navigate through!	11/13/2019 10:55 AM
17	Yes however like the EHCP this assumes your child will go to an establishment to receive the education. It does not take into account the need for children who are unable to attend any form of institution. In addition there is no cross county engagement to understand what other counties like CCC have to offer to assist e.g. Red Balloon & Red Balloon Air	11/13/2019 9:53 AM
18	It is not easy to find or understand. Other LAs have a much more substantial and relevant offer, that is not open to us.	11/13/2019 9:42 AM
19	University student and studying education.	11/12/2019 7:42 PM
20	It does not go far enough and needs further development, particularly around ASD and particularly for those parents who can identify a demand avoidant profile.	11/12/2019 7:23 PM
21	I know about it but I don't really know enough about it	11/12/2019 7:11 PM
22	My eldest daughter accessed that service. Was told they can't help Grace till she is 18.	11/12/2019 1:22 PM
23	Yes, CBC updated it a couple of weeks ago in anticipation of the CQC inspection. It's still hard to navigate.	11/12/2019 1:00 PM

Q19 If you HAVE used the 0-25 Central Bedfordshire SEN & Disability Local Offer, how well did you find what you were looking for?

Answered: 98 Skipped: 58



ANSWER CHOICES	RESPONSES
Very easily and quickly	3.06% 3
After a bit of a search I found what I needed	22.45% 22
It took a long time but I eventually found what I needed	25.51% 25
Couldn't find what I needed	43.88% 43
TOTAL	98

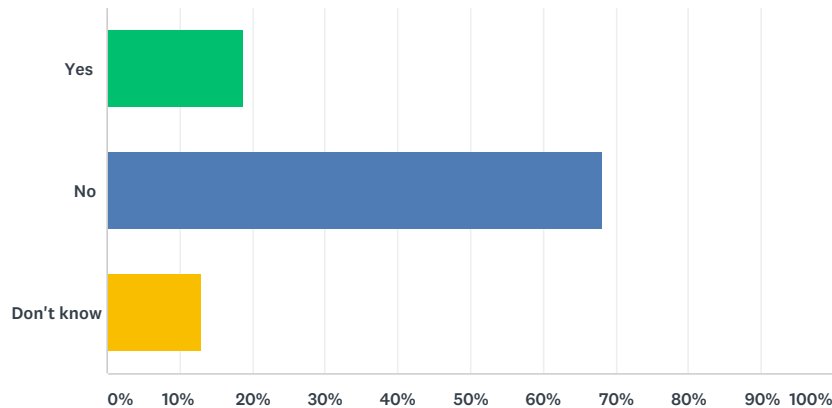
#	COMMENTS:	DATE
1	N/A	11/17/2019 3:39 PM
2	Was looking at what Alternative Provision was available rather than mainstream school. Child's consultant contacted CBC for information about more emotional support for child. Consultant was told there is none?	11/17/2019 2:17 PM
3	I think there has been some improvement I use to find it impossible to find information.	11/17/2019 12:37 PM
4	Found the central beds website not user friendly and difficult to navigate. Often not able to find the information I am looking for.	11/17/2019 11:53 AM
5	It was by word of mouth I heard	11/17/2019 4:32 AM
6	See above	11/16/2019 10:25 PM
7	Had to join the coffee mornings with other parents to make sense of it	11/16/2019 8:39 PM
8	I've found things quicker by searching the internet myself.	11/16/2019 7:09 PM
9	It's all changed and cant find stuff	11/16/2019 6:57 PM
10	Not used it	11/16/2019 3:35 PM
11	Needs improvement. Basic info provided.	11/16/2019 3:28 PM
12	I didn't know about it	11/16/2019 3:15 PM
13	Haven't had chance to read it yet.	11/15/2019 7:47 PM
14	No help for eating disorder on the local offer	11/14/2019 10:10 AM
15	Extremely difficult to find. Nobody really knows what it is, schools should promote this to parents.	11/13/2019 11:38 PM
16	Do not know about this at all	11/13/2019 7:49 PM
17	Again most provision is to the west of the county!	11/13/2019 6:12 PM
18	It is a good tool to help parents	11/13/2019 3:07 PM
19	No actual support. Just a list!	11/13/2019 12:11 PM
20	It is so difficult to search for what you need. Additionally there is very little for under 5s, particularly if they are physically disabled.	11/13/2019 11:39 AM
21	It has improved but still not easy to navigate through.	11/13/2019 10:55 AM

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22	See above.	11/13/2019 9:53 AM
23	Nor did I know what I was looking for to help my child.	11/13/2019 9:42 AM
24	Its unclear on the website	11/12/2019 7:23 PM
25	Haven't used it	11/12/2019 7:11 PM
26	I don't find it very useful.	11/12/2019 1:26 PM
27	Sometimes I couldn't find what I needed	11/12/2019 11:33 AM

Q20 Do you feel your child/young person has the help they need to achieve their best possible outcomes?

Answered: 154 Skipped: 2



ANSWER CHOICES	RESPONSES	
Yes	18.83%	29
No	68.18%	105
Don't know	12.99%	20
TOTAL		154

#	COMMENTS:	DATE
1	But agencies need to work together for a cohesive outcome for my daughter	11/17/2019 3:55 PM
2	I feel that my daughter is lucky to be attending a school with a headteacher who is so impassioned to help each individual child and young person to achieve. However, if she were to leave this setting, I feel we would be back to a place of despair as we were for the last few years. I believe it is incredibly sad that the SEN children and young people are reliant on one individual to help them to achieve amazing things. I feel that the education system is completely broken. It saddens me as someone who is a qualified teacher to see how badly children and young people with any difference are treated. I feel that the health system try their hardest, but with so little money, they can not do everything, and sadly it can be those who are most vulnerable who suffer. I am petrified about the future when I am not around anymore to fight the system for my child. Having lost most of my fight last year during that terrible time, I saw how easy it was to get lost and ignored. I don't want this to happen for my daughter.	11/17/2019 2:36 PM
3	Different therapies may have been more helpful for child who finds it difficult to verbalise how he feels. Different setting to suit his learning style would be brilliant.	11/17/2019 2:17 PM
4	Not yet. But I hope that will come after assessment.	11/17/2019 1:23 PM
5	I feel she's not a problem to them so needs no help to reach anything like a liveable potential. She is high functioning and totally able to reach an independent life with support now!	11/17/2019 12:50 PM
6	No idea how to help him progress as too long between appointments.	11/17/2019 12:37 PM
7	I'm not sure yet due to the change of schools. All I do know is the education my son has missed out on has put him behind. The trauma he has experienced in a provision that wasn't monitored will be etched on him forever. I have lost all trust in CBC SEND team and I will never forgive them for allowing these extensive failures.	11/17/2019 12:04 PM
8	The recourses are just not available to provide what our children need to improve their outcomes. The EHCP process is to difficult to navigate for all involved and means that Provision is not adequately identified, specified or provided for our children's to ensure they can make progress and achieve their potential outcomes.	11/17/2019 11:53 AM
9	I feel its a case of googling what he needs and not accepting "no" as a final answer	11/17/2019 11:28 AM
10	I feel we've waited too long - still awaiting official help although school are amazing	11/17/2019 10:42 AM
11	It seems impossible to get the support again because she is not physically aggressive AT SCHOOL and does not and never will be eligible for an ehcp	11/17/2019 4:32 AM
12	Not yet no	11/16/2019 10:54 PM
13	In some areas yes ie the sen team.at cbc have been great. Really supportive and advising. I feel completely let down by health though	11/16/2019 10:27 PM
14	School needs more training.	11/16/2019 10:25 PM
15	My daughter NEEDS more support in school as much as ANY child with sen needs, just because she masks doesn't mean she is any less deserving.	11/16/2019 10:16 PM

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16	Yes now after a long battle at tribunal. He missed 3 years plus of useful education prior to this.	11/16/2019 9:13 PM
17	Educationally I am more confident now that he attends a provision where his needs are better understood. In terms of the support with speech and OT absolutely not. In fact I will be astounded if his reading and writing is not chronically affected by his speech issues.	11/16/2019 8:39 PM
18	More so from us as parents and the excellent provision they are in rather than LA services	11/16/2019 7:12 PM
19	I have to fight for any little help and his deteriorated because of this!	11/16/2019 6:57 PM
20	My eldest daughter hasn't been seen By an educational psychologist since 2016 her current school are making a new referral	11/16/2019 6:36 PM
21	I feel that everyone tries there best but quite often there information is conflicting and it gets very confusing at times	11/16/2019 6:31 PM
22	My child needs weekly intervention, only just started fortnightly nursery nurse sessions	11/16/2019 6:26 PM
23	More focus needed on social skills and emotional health Restricted access to specialist services such as educational psychologist	11/16/2019 6:21 PM
24	He masks at school. So no support. Diagnosis not yet met. School making out that I'm making issues at home up. Not listening to me.	11/16/2019 4:38 PM
25	Yes, only after being successful at tribunal. LA were proven to be inadequate and incompetent. My son now receives the care and education he needs, however, this is out of county as Bedfordshire have no suitable provision and are incompetent.	11/16/2019 3:28 PM
26	At this present time	11/16/2019 6:42 AM
27	Been let down by his school	11/15/2019 7:47 PM
28	EHCP - not specific, not quantified, they do not indicate the provision the child needs to go to therefore most mainstream schools will say they can support when they can't. schools are not supporting EHCP process and are doing their own system. Schools are getting out of supporting with woolly wording. School and CBC Will not implement/define 1:1 support even if the child needs this. TAs are not trained in ASD. Most children are just made to fit the system. They are not assessing the needs of the child, instead are looking at what the mainstream school can do to support them instead. Staff not trained are doing salt sessions and OT sessions with no professional input or indication of levels needed. All these will contribute to children not achieving their potential and falling behind their peers.	11/13/2019 11:38 AM
29	As a high functioning autistic our son struggles socially. He is very intelligent and we feel that the attitude is that if he is hitting academic targets then they dont need to intervene. He spends most days playing on his own.	11/13/2019 7:33 PM
30	My son is getting further and further behind. The school are refusing to put in adequate support. His behaviour and self esteem and confidence are now being affected. The only thing they are interested in is putting him on ADHD medication.	11/13/2019 6:41 PM
31	Not currently She has mental health issues Currently only attends 2 hours of school per week	11/13/2019 4:44 PM
32	There are some areas that are good but the lack of literacy support has had a huge effect on him.	11/13/2019 3:07 PM
33	We find ways to bridge the gaps for my son but only because I am very proactive	11/13/2019 12:40 PM
34	No way, it's only with our help they'll get anywhere and we're not even at middle school yet, we're resigned to the fact that our children may not even work because of the shortfall from their ehcplan	11/13/2019 12:08 PM
35	The SEND team specifically are blocking my son from reaching his potential by cutting down his special needs provision.	11/13/2019 11:39 AM
36	I am concerned for his mental health as he gets older.	11/13/2019 11:00 AM
37	We are getting there though	11/13/2019 10:44 AM
38	Currently only receiving maths english and science for 6 hours a week. No other subjects, Does get weekly / fortnightly counselling with her CAMHS psychologist. A Personal Guidance Advisor has been nominated however only just named and first meeting held, without our daughter present.	11/13/2019 9:53 AM
39	We are let down on a daily basis.	11/13/2019 9:42 AM
40	Needs speech therapy to aid communication , occupational therapy to support his sensory needs and access to suitable social clubs in my area	11/13/2019 9:33 AM
41	Still fighting. Requires formal complaints and appeals to be raised in order to have needs met.	11/12/2019 7:23 PM
42	They do now	11/12/2019 1:35 PM
43	No, he needs a mainstream autism unit place NOW. He's unlikely to get one EVER. He's just spent the morning in the Head's office and on a part time timetable. He is a massive drain on the resources of his mainstream school, it's not fair on them or him.	11/12/2019 1:26 PM
44	We have been totally failed, forgotten about, abandoned.	11/12/2019 1:22 PM
45	At the moment yes, but in a couple of years when he needs a place in an Upper School autism provision, there will be nothing available and I will probably end up home educating him AGAIN.	11/12/2019 1:00 PM
46	I am doing my best for the children, they are let down by inadequate services.	11/12/2019 12:22 PM
47	I get ping ponged between education and health Have given up work to be able to sort appointments and chasing reports.	11/12/2019 11:33 AM

Q21 Do you feel there is anything that Central Bedfordshire Council and the Health Authority could change to make things easier for your child/young person and your family?

Answered: 126 Skipped: 30

#	RESPONSES	DATE
1	Assist at schools for more support. Pre-diagnosis and after at mainstream settings	11/17/2019 5:05 PM
2	Information and stop schools being gate keepers.	11/17/2019 4:36 PM
3	Could use more help signposting to different agencies that can help	11/17/2019 3:55 PM
4	We need more special schools or more mainstream schools with specialist units. Every school I have looked at is at full capacity and at least 30 minutes from my home. It would also be impossible to get my son to his mainstream setting and take my daughter to her specialist setting for the same time start in the mornings if we were to apply for somewhere with no transport. We would be very happy to see a school open closer to Flitwick, Ampthill, Maulden, Toddington area of Central beds.	11/17/2019 3:39 PM
5	Communicate. Consider how my child is not a burden to the community, but could enhance it. Listen to us when we admit we need help and support. I get so overwhelmed and Unsupported for such a ping time and had nowhere to go. Have recently found Freddie and friends sunshine stop Group, and know that had there been a place to attend during this time where I could talk to other parents, perhaps my own mental health would not have deteriorated the way that it has.	11/17/2019 2:36 PM
6	encourage Adacademies and Parents to help each other. Provide funding for better transition from primary to secondary school. Teachers and SENCO's should not assume that they know what they are dealing with. They need to make time listen to concerns. The law says to fine parents for school non-attendance. Do the administration costs exceed the income? More therapies (not just talking, counselling) required as people find it difficult to verbalise how they feel and what has happened to them. Trauma Informed therapies?	11/17/2019 2:17 PM
7	Conduct the tender for school transport in a 3 or 5 year basis.	11/17/2019 2:06 PM
8	Train the school more	11/17/2019 1:42 PM
9	Yes	11/17/2019 1:22 PM
10	Some support and interest from CBC would be helpful	11/17/2019 1:16 PM
11	Stop schools being the gate keepers!	11/17/2019 12:50 PM
12	Lack in service	11/17/2019 12:42 PM
13	Yes stick to time constraints. We have been waiting since 2017 for an updated EHCP since have had two annual reviews and never even a communication to say that they have received it or are/are not amending. LA have not looked at his EHCP since 2017. School is working from a plan made for him when he was in nursery.	11/17/2019 12:37 PM
14	Not sure	11/17/2019 12:18 PM
15	Yes to implement what they write into schools, as school preachers it but doesn't do it because they don't have to use an IEP/SMART Targets so no involvement with parents	11/17/2019 12:17 PM
16	Answer their phones. Allocated officers should be monitoring children's progress on a regular basis!	11/17/2019 12:04 PM
17	Listen to our genuine concerns and those professionals who know the child well and dont ignore Us or fob us off. Review annual review paperwork in the timescale you are required to be law, we are expected to comply but you do not.	11/17/2019 11:53 AM
18	Listen to the parent more	11/17/2019 11:28 AM
19	Quicker referral process	11/17/2019 10:42 AM
20	Improving time scales and more support	11/17/2019 9:25 AM
21	Listening to us as parents, preparing for adult independence.	11/17/2019 9:21 AM
22	Educate the school to be implementing their SEND plans	11/17/2019 9:01 AM
23	More staff, better support in the community, a lot more education needed in schools to help teachers understand how to teach kids with SEN.	11/17/2019 8:38 AM
24	Communication!!!	11/17/2019 7:54 AM
25	Yes. Support for autistic girls and their families and an understanding about masking. The support should be there for the child and the family. Just because a child is bright, it does not mean they don't need support. Long term mental health is a poor prospect when your child already self harms and has depressive thoughts due to lack of understanding by council and school and over-demand on services at CAMHS.	11/17/2019 4:32 AM
26	Improve adult services. Once a child turns 18 so much of the support disappears but their needs do not change overnight.	11/16/2019 11:59 PM
27	Services need to be more joined up	11/16/2019 11:13 PM

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28	Make referrals easier	11/16/2019 11:02 PM
29	Faster turnarounds - know resourcing related	11/16/2019 10:54 PM
30	I get that there are delays but what help is available during this time?	11/16/2019 10:27 PM
31	More advisory teachers/training for schools. More overview of SEN within schools although most schools are academies so don't know what authority they would have.	11/16/2019 10:25 PM
32	Make schools offer support to ALL sen diagnosed children not just to those who get financial funding for the school.	11/16/2019 10:16 PM
33	More specialist schools and/or specialist teachers within mainstream	11/16/2019 9:47 PM
34	Sometimes the wait is ridiculous to be seen. Reducing the wait to see specialist like the OT for example would enable quicker progress with changes that really do make a difference for our son.	11/16/2019 9:47 PM
35	Once diagnosed you should be given more support & resources	11/16/2019 9:23 PM
36	Yes too many things to list here	11/16/2019 9:13 PM
37	Encourage services to work together more to support young people	11/16/2019 8:55 PM
38	Give my son SALT intervention and implement occupational therapy advice and review as multiply recommended in order that this placement has the best chance of success	11/16/2019 8:39 PM
39	Make getting a diagnosis easier and quicker	11/16/2019 8:37 PM
40	Shorter time scales for appointments. Easier to access Edwin Lobe instead of being told you need to produce more evidence. When clearly there has been a problem with the child for four years.	11/16/2019 8:37 PM
41	To be able to speak with the Send team direct and for them to reply back to you. To be able to get appointments eg Edwin Lobe and other health care professionals within a reasonable time frame. For professionals to take ownership for your child's condition and not to be passed around.	11/16/2019 8:18 PM
42	Provide a keyworker for my son who sees all information about him from every source, understands the contents of his EHCP, and communicates and liaises with all the services that he uses	11/16/2019 7:19 PM
43	Better understanding and preparation for adulthood. Better pathways for Children with disabilities	11/16/2019 7:12 PM
44	Better guidance and support	11/16/2019 7:11 PM
45	Central beds could actually answer the phone or respond to emails. sEND officers could be more knowledgable and actually deliver on their promises. Central beds could apply the law where things like EHCPs and needs re-assessments are concerned instead of gibbing parents off and leave them waiting.	11/16/2019 7:09 PM
46	Make sure transport is sorted for when they start school , my son had 5 weeks off school because of this .	11/16/2019 7:09 PM
47	Shorter waiting times. We applied to chums in January 2019 and had workshop in October 2019, to diagnose SPD, workshops for children for SPD, or suspected SPD.	11/16/2019 7:00 PM
48	Actually have permanent speech therapists in post for special schools and not rely on short term locums	11/16/2019 6:59 PM
49	Funding	11/16/2019 6:57 PM
50	Work together better, offer services instead of waiting to be asked	11/16/2019 6:54 PM
51	Follow up appointments after diagnosis. Easier to get A EHCP	11/16/2019 6:53 PM
52	The current send team routinely break legal deadlines, do not communicate with parents and are imposing illegal criteria in their decisions whether to assess. Delays are lengthy and they willingly lie about children's needs.	11/16/2019 6:41 PM
53	Update their EHCPs promptly!	11/16/2019 6:36 PM
54	More autism provisions In the local area. Monitor schools so the Ardley J	11/16/2019 6:36 PM
55	Training for school staff	11/16/2019 6:32 PM
56	Yes but not quite sure what	11/16/2019 6:31 PM
57	Provide ehcp/ salt etc	11/16/2019 6:30 PM
58	Early intervention is highly important as well as children having access to both deaf and mainstream education and groups	11/16/2019 6:26 PM
59	Listen to the parents concerns and take them seriously! Health and education need to work together	11/16/2019 6:21 PM
60	Better communication and time keeping.	11/16/2019 6:16 PM
61	More funding for schools to employ 1-1 support for said child/children and give them the support they so desperately need instead of being left in a class with little support	11/16/2019 5:46 PM
62	More help.	11/16/2019 4:38 PM
63	Listen and act the first time a family says they are struggling to cope	11/16/2019 4:26 PM
64	Access to correct educational setting with appropriate support.	11/16/2019 4:19 PM

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65	Actually talk to each other would be a start	11/16/2019 3:40 PM
66	Better sign posting	11/16/2019 3:35 PM
67	Make more places for SEN they do not like busy loud places and times make them more decent times/days for SEN	11/16/2019 3:35 PM
68	Where do I start ! Listen to parents and stop being so arrogant. Think of the needs of the child and not just the cost.	11/16/2019 3:28 PM
69	There needs to be more communication between schools and parents	11/16/2019 3:15 PM
70	More transparency, shouldn't have to search for things.	11/16/2019 3:14 PM
71	One contact point could make it easier to get the help you need	11/16/2019 3:07 PM
72	Groups to attend to involve with sports and activities. Plus life skills	11/16/2019 2:58 PM
73	Early intervention (staff knowing how to spot families in need)	11/16/2019 12:14 PM
74	Work cohesively and follow the specialist paediatrician advice	11/16/2019 10:16 AM
75	Easier access to find help/support/groups in our community	11/16/2019 6:42 AM
76	Send ofsted into the special schools	11/15/2019 7:47 PM
77	Yes. Make services available and accessible. Children are not going to reach their maximum potential if they don't have early years support.	11/15/2019 2:29 PM
78	Coordinated services	11/15/2019 8:19 AM
79	More specialised support for families with adopted children, especially as these families often have multiple children with additional needs. Education, respite, social support is only ever considered for each individual child and the whole family unit, with all the children's needs is never taken into consideration. Life is a continual battle trying to support these children and fight for each of them to enable them to achieve their potential. But it is a continual uphill struggle. The services needed for families in this position eg respite are almost impossible to get as each child may not warrant it by themselves but with a number of children in a similar position within the family, should enable these parents to receive much more support.	11/14/2019 8:57 PM
80	Be honest with parents	11/14/2019 8:17 PM
81	Make more special schools available, and have appropriate trainings for teachers/sen staff to better know how to help children with sen needs. Smaller classroom sizes would be a bonus.	11/14/2019 11:12 AM
82	Have a named person who is in charge and coordinates school and health and ensures working together happens	11/14/2019 10:10 AM
83	Work together, not to give false information, stick to legislation, don't stop parents raising for EHCP, offer more understanding and support, direct to support networks and charities, answer the phone, stop parents having to chase and shout to get support, write ehcp in line with legislation, stop taking parents to tribunal over school placements and sections b and f, work with preschools and schools more to enforce ehcp and sen support, reviewing exceptional needs funding termly by an assessment is extremely stressful with the threat of it being taken away, health care and cbc work together at assessment stage to highlight needs in the ehcp	11/13/2019 11:38 PM
84	Waiting times for assessments	11/13/2019 9:43 PM
85	By not turning away children who apparently don't meet criteria or have a service before the Edwin Lobo for input	11/13/2019 8:57 PM
86	See above comments. I feel that my children are a bit lost in the system, being diagnosed in Buckinghamshire camhs, but living and going to school in Bedfordshire. I rarely get invited to meetings at school that are specifically about my children's needs. More sessions for workshops etc in Dunstable area and in evenings would be helpful.	11/13/2019 8:26 PM
87	Yes communicate with the school, make the process for an EHC more straightforward, when a parent is struggling with a school intervene!	11/13/2019 7:58 PM
88	yes, communicate all the benefits that our son is entitled to. we have found out by default.	11/13/2019 7:49 PM
89	make sure schools work with parents and respect their Decisions for their children	11/13/2019 7:41 PM
90	Give me child support at school. Give the school more funding. Make special needs / disabilities a priority. My child needs to survive in society in the future and we want her staying in mainstream for as long as possible but you are making it impossible. The council claim that it wants to support SEND but I certainly am not convinced.	11/13/2019 7:37 PM
91	Some acceptance of the need to support young people from a more holistic approach.	11/13/2019 7:36 PM
92	Make the referral process for schools compulsory after assessments in pre school.	11/13/2019 7:33 PM
93	Provide the funding to schools and stop making it so utterly impossible to get adequate support.	11/13/2019 6:41 PM
94	Yes - they need to work together more and look at the geographical implications	11/13/2019 6:12 PM
95	Treat each child as an individual and listen to parents more. They know their own children	11/13/2019 4:44 PM
96	Having visited another school to maybe move our son, we saw a completely different approach to SEND Support. Why is it that different schools provide different quality support? Who monitors the provision? Who monitors notional budget spending? Can CBC develop a 'best practice' and 'recommended support packages' guide for SENCOs? Standardise the marking and assessment in year 4, by suitable moderation.	11/13/2019 3:20 PM

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97	Yes. More oversight and monitoring of how schools are spending the notional budget. To improve schools that are not delivering appropriate support, to ensure all schools can deliver the same high quality support. To ensure staff are trained to help any anxious children. To ensure that assesment in Y4 is externally moderated carefully.	11/13/2019 3:07 PM
98	speed things up and stop passing us from one place to another.	11/13/2019 1:18 PM
99	They need to find s way to help them join the community. Not by socialising separately but by bringing communities together and offering inclusive services	11/13/2019 12:40 PM
100	Provide a case worker for each family.	11/13/2019 12:11 PM
101	Info, info,info and funding	11/13/2019 12:08 PM
102	Work together, meet the child and parents	11/13/2019 12:05 PM
103	They could listen to the professionals around my son who do not agree with their EHCP plan. They could accept that some changes need to be made to the EHCP plan. They could engage in discussions with me and his team to ensure the plan they are forcing us to comply with actually meets his needs.	11/13/2019 11:39 AM
104	Support from social care. Support for mental health.	11/13/2019 11:00 AM
105	yes, Preparing for adulthood needs improvement	11/13/2019 10:55 AM
106	Clear/better signposting	11/13/2019 10:20 AM
107	Yes - talk to each other, work with each other and provide a full wrap around service when this is needed. Don't make it a battle for parents to have to fight every step of the way.	11/13/2019 9:53 AM
108	Everything. Make the services more clearly available, especially at the time of diagnosis. Understand that certain conditions require the input and communication from more than one service. Involve parents every step of the way so that they are not fighting to find out what support their child needs and for that support to be put in place. Stop parents having to quit their jobs to take on this mammoth task.	11/13/2019 9:42 AM
109	Regular SALT, access to OT assessments, local clubs for autistic children and their families	11/13/2019 9:33 AM
110	Working together, not just BCCG but hospitals outside Bedfordshire as not all children are seen locally. Low the children services thresholds otherwise adult services have to pick up years of not support and it cost a lot more in the long run to support the child.	11/13/2019 7:46 AM
111	Providing the correct school place without too many transitions just because the recommendation by Warnock is to keep all children in a mainstream school. My daughter faces a lot of exclusion rather than inclusion. Human rights entitle her to an education but doesn't state where or how!!	11/12/2019 7:42 PM
112	Improving services for children/ young people with ASD specifically SI OT availability and SALT for social communication difficulties. A joint.position statement needs to be developed on PDA and families need further support from health to provide education to school. Schools find it a challenge to meet this profile well - need specialist provision.	11/12/2019 7:23 PM
113	Provide access to ongoing support after diagnosis of autism. So many questions	11/12/2019 7:11 PM
114	Listen to parents / children and young people, train schools in supporting sen children, effectively implement early intervention. Take responsibility and be accountable. Respond to calls and emails	11/12/2019 6:30 PM
115	Provide free information sessions on adhd and management of this	11/12/2019 5:44 PM
116	To provide more information and funds plus help with Homelife. For an example Occupational Therapy I have been on the waiting list for a long time and my son really needs extra room for all his sensory needs as he suffers from sensory processing disorder plus I've also asked for and for a bath to be fitted in as my son really struggles with the shower due to his anxiety	11/12/2019 4:10 PM
117	Social care could do something - anything.	11/12/2019 4:03 PM
118	No	11/12/2019 2:03 PM
119	Do full assessments in one go. When you get a multi disciplinary appointment actually seeing all those who need to be involved, not just one Dr!	11/12/2019 2:02 PM
120	A more personalised service, particularly from Social Care. They throw money at us to pay for direct payments but that isn't always easyto manage. We need a service that can meet our daughters needs.	11/12/2019 1:58 PM
121	There are so many autistic children struggling with mainstream school. CBC should do some in depth research on this and work towards providing the support needed for these exceptional children.	11/12/2019 1:26 PM
122	Commission OT provision for sensory processing needs; upskill local ASD assessment teams to be aware of PDA and non-stereotypical presentations of ASD; provide training and regular scrutiny of schools to ensure they understand and can comply with the SEND Code of Practice; increase CAMHS provision for those Under 11	11/12/2019 1:23 PM
123	More autism provision units in GOOD and OUTSTANDING schools.	11/12/2019 1:00 PM
124	More support in school Be prepared for a long wait	11/12/2019 12:28 PM
125	Better access to resources, more reliable application process for EHCP, for CAMHS to actually do their job and assess children instead of passing the buck.	11/12/2019 12:22 PM
126	Would like a named person so when I'm going ponged about I have a person to go, to who school and health are accountable to. Would like school, health and local authority to be accountable.	11/12/2019 11:33 AM

Q22 Is there any piece of advice you could give parent carers who are at the start of their journey?

Answered: 125 Skipped: 31

#	RESPONSES	DATE
1	Join as many groups and get as much information as you can	11/17/2019 5:30 PM
2	Reach out and get support where possible	11/17/2019 5:05 PM
3	Talk to snap	11/17/2019 4:36 PM
4	To use the services provided and chase them up regularly otherwise you get forgotten about	11/17/2019 3:55 PM
5	Keep fighting For your child! When you can't fight any more, find a group of people who will help you to fight against the broken system.	11/17/2019 2:36 PM
6	Contact Parent Partnership, SENDIASS, Carers In Beds, make a nuisance of yourself because your child will be left behind if you don't stand up for them.	11/17/2019 2:17 PM
7	Seek all the help that you can, it will lighten the load.	11/17/2019 2:06 PM
8	Research	11/17/2019 1:42 PM
9	Always go with your instincts and believe in your child and don't be afraid to disagree and put in oppersitional action as it tends to be proven right. Learn the SEND and children's and families act 2014, learn the law. Find schools earlier than normally.	11/17/2019 1:22 PM
10	They need a lot of strength and a lot of luck and they need to able to battle constantly with schools and CBC if they want to get anywhere	11/17/2019 1:16 PM
11	Get ready to fight and be that parent. It won't come without extraordinary efforts and time!	11/17/2019 12:50 PM
12	Help children / parents	11/17/2019 12:42 PM
13	Teach yourself everything you can to empower yourself. Go on courses, join the parent form, anything you can so you don't get fobbed off. You know your child the best learn what it is they need and what they are entitled to. And fight for it. Because fight is what you have to do!	11/17/2019 12:37 PM
14	Never give up and always fight for your child	11/17/2019 12:18 PM
15	It's going to be a hard fight, mentally very draining, frustrating because you don't get anywhere. Try and support your children in anyway possible	11/17/2019 12:17 PM
16	Start the process early	11/17/2019 12:06 PM
17	Be forceful but Send team will not take action unless you push and push! This is so wrong when we are dealing with vulnerable children.	11/17/2019 12:04 PM
18	Be prepared to fight for the help, support and provision your child needs as it's an ongoing battle with services being cut. Learn as much about the EHCP and annual review process as possible as it is unnecessarily complicated to ensure you can ensure that your child's EHCP is being updated correctly by all involved, be prepared to obtain private professional reports for detailed, specified and quantified provision as you won't get this from local authority employed professionals and be prepared to go to tribunal to ensure your child gets the provision they need as CEntral beds seem to contest even minor provision that may have even a minor cost attached to it	11/17/2019 11:53 AM
19	Don't accept the first answer you get - if you are not happy then keep pushing	11/17/2019 11:28 AM
20	Be strong, don't give up, push for what your child needs	11/17/2019 10:42 AM
21	Never give up. You know your child better than anyone. Never feel alone because there are so many others in similar situations.	11/17/2019 9:25 AM
22	Early diagnosis, talk to schools and health professionals as much as you can about support for your child, they won't get through school without it.	11/17/2019 9:21 AM
23	Don't take no for an answer. Educate yourself on what your child's rights are. Educate yourself on what opportunities there are out there for your kids. Talk to parents who have been through it already.	11/17/2019 8:38 AM
24	Arm yourself with all the information you can	11/17/2019 7:54 AM
25	Be prepared for a long journey, a huge battle to get seen at the cdc and constant battle with all services - at the detriment of your own mental health. Autism Bedfordshire and the Avenue are your only hope if your child is high functioning. Good luck	11/17/2019 4:32 AM
26	Warn them that everything has to be fought for and to constantly be in tie ball to ensure their child is getting what they needs.	11/16/2019 11:59 PM
27	Be their voice	11/16/2019 11:38 PM
28	Be prepared to fight!	11/16/2019 11:13 PM
29	Fight to be heard and to get the help needed	11/16/2019 11:02 PM
30	That they are going to have to push to keep on top of things and that the experience they are going to have is so hugely dependent on the school	11/16/2019 10:54 PM

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31	Be persistent to be heard	11/16/2019 10:27 PM
32	I don't know...I was in a privileged position of knowing the SEN.	11/16/2019 10:25 PM
33	Be public and open, if schools don't support you, shout!! School is the main port of call for many children.	11/16/2019 10:16 PM
34	Get as much info as they can and accept all help offered	11/16/2019 9:47 PM
35	Keep fighting for your child. Jump through the hoops required of you and seek honest and realistic feedback.	11/16/2019 9:47 PM
36	Talk to other parents and don't just take what the School says. If you're not happy then fight your corner.	11/16/2019 9:23 PM
37	Seek info from as many sources as possible	11/16/2019 8:55 PM
38	Move to a different county? OK, so everywhere has its own problems, but I would want them to be aware of the agendas - SEN wanted to put our 5 yr old into Ardley Hill ASD provision where his anxieties would be exacerbated by the Yr 5 and 6 children, despite the presenting issues being more mental health than ASD. I was confused until I heard from other parents about an alleged assault by a member of staff on a child and the subsequent uproar of children being moved. No wonder they wanted to fill up the empty chairs. There's always a bigger picture.	11/16/2019 8:39 PM
39	Hang in there	11/16/2019 8:37 PM
40	Be prepared to go into a long battle! And don't give up.	11/16/2019 8:37 PM
41	You have long journey ahead and be prepared for a fight on your hands. Never give up!	11/16/2019 8:18 PM
42	don't be afraid to fight and be pushy to get what your child needs	11/16/2019 7:51 PM
43	Don't give up hope, fight for your child's needs	11/16/2019 7:34 PM
44	Hold on tight - its going to be a rollercoaster ride! Make connections with other parent carers and local charities providing support. Understand the law - knowledge is power. Don't just accept what you are told, inform yourself and make your own decision. Get involved with other parents and work collectively for change	11/16/2019 7:19 PM
45	Always have people around you that support you. Make sure you get as much information on your rights and the law	11/16/2019 7:12 PM
46	Fight! Try and learn all you can about SEND law because central beds seem to have no clue and you will need the information.	11/16/2019 7:09 PM
47	You have to constantly be on the phone to the council	11/16/2019 7:09 PM
48	To join groups to speak to other parents. They have best advice	11/16/2019 7:00 PM
49	Find private OT, speech and sensory therapists as the service is non-existent in reality in Central Beds	11/16/2019 6:59 PM
50	Learn the Law and fight every bit of the way	11/16/2019 6:57 PM
51	Be brave and remember that your voice is important	11/16/2019 6:54 PM
52	Ask many questions and do lots of research.	11/16/2019 6:53 PM
53	Be prepared for the send team to fail your child repeatedly and damage their mental health with their long delays and illegal decisions	11/16/2019 6:41 PM
54	Never give up.	11/16/2019 6:36 PM
55	Ring and pester central beds council a lot as they don't get back to you and take a long time do anything my daughters have had echps for 4 years and we haven't done a review with a final copy yet as they don't finalise them in time we always use drafts	11/16/2019 6:36 PM
56	Have allot of patience and push for your child's help	11/16/2019 6:32 PM
57	Have everything written down in front of you. Don't be afraid to ask questions or for help and always trust you gut instinct	11/16/2019 6:31 PM
58	Get evidence for everything. Document everything.	11/16/2019 6:30 PM
59	Make your voice heard	11/16/2019 6:26 PM
60	Don't give up	11/16/2019 6:21 PM
61	Stay strong.	11/16/2019 6:16 PM
62	Stand your ground as sometimes schools and health professionals tend to not listen to	11/16/2019 5:46 PM
63	No advice. Still 4 years in with diagnosis or support.	11/16/2019 4:38 PM
64	Shout loud	11/16/2019 4:26 PM
65	Join support groups who have independent, good knowledge of local services, and will help you access support that you would not be made aware of.	11/16/2019 4:19 PM
66	Move away	11/16/2019 3:40 PM
67	Be persistent	11/16/2019 3:35 PM
68	I already give people advice and share my experiences I've had with my child	11/16/2019 3:35 PM
69	Don't trust the LA. They only think about costs and not the needs of the child. Talk to parents in the same boat.	11/16/2019 3:28 PM

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70	Keep going on at the schools if they aren't listening and carry on the battle	11/16/2019 3:15 PM
71	Google everything to find what you are entitled to and where you can take your child to interact with children like them. Also you will have to fight for everything you should have.	11/16/2019 3:14 PM
72	Don't give up	11/16/2019 3:07 PM
73	Stick to ur guns.	11/16/2019 2:58 PM
74	Don't give up. Keep looking for help it's there for you and your child!	11/16/2019 2:19 PM
75	Look for organisation that can help support you to get the right support as without that you won't get anywhere with cbc	11/16/2019 12:14 PM
76	Access SEN support from charities	11/16/2019 10:16 AM
77	Keep fighting for what you know your child needs, you are their parent and know what is best	11/16/2019 6:42 AM
78	Ask for help	11/15/2019 7:47 PM
79	Give up your job, join as many support groups as possible and try to implememnt help and therapies at home	11/15/2019 2:29 PM
80	Good luck. Don't be fobbed off. Don't try to be nice it won't make any difference. Escalate earlier rather than later.	11/15/2019 8:19 AM
81	Talk to other parents of children with needs and be prepared to fight for everything unfortunately!	11/14/2019 8:57 PM
82	Move out of this area	11/14/2019 8:17 PM
83	Good luck.	11/14/2019 11:12 AM
84	go on training courses and get a lawyer	11/14/2019 10:10 AM
85	Apply for an EHCP yourself and appeal, fight everything, do your research and read all legislation as you will receive constant misinformed information that has been fed down from the LA	11/13/2019 11:38 PM
86	Seek support as you are not alone	11/13/2019 9:43 PM
87	Chin up, keep fighting	11/13/2019 8:57 PM
88	Keep fighting! Don't take no for an answer and become a pain to make sure you are listened to!	11/13/2019 7:58 PM
89	yes, persist, do not accept 2nd best.	11/13/2019 7:49 PM
90	Hang in there, it's gets better over time.	11/13/2019 7:41 PM
91	Start early - do not want TIL reception for an ehcp because they put problems in the way so takes time to push forward. Early intervention is key	11/13/2019 7:37 PM
92	Help yourselves as no one else will help you.	11/13/2019 7:36 PM
93	be prepared to be ignored.	11/13/2019 7:33 PM
94	Don't give up and keep fighting.	11/13/2019 6:41 PM
95	Don't give up, it won't be an easy journey and you will have to fight for what your child needs as nobody else will. Ask lots of questions of everyone.	11/13/2019 6:12 PM
96	Do not give up. Do not let ANYONE fob you off. Keep strong. Ask questions.	11/13/2019 4:44 PM
97	Don't expect too much help. You will have to work hard and fight for what you child needs. Don't be afraid to change school. Know the local offer and get help from the various local services. Link up with other parents in similar situations - you are not alone! Don't give up.	11/13/2019 3:20 PM
98	Read the Code of Practice and be ready to fight and stand your ground. Be reasonable in what to expect - there are tight budgets. However, good use and careful planning does get results. Never give up.	11/13/2019 3:07 PM
99	don't expect to get anywhere without constantly chasing, reminding, and pushing for help.	11/13/2019 1:18 PM
100	Keep fighting for your child's rights.	11/13/2019 12:11 PM
101	Trust yourself and don't take what the "professionals" tell you as gospel, do your research and hope you have a strong enough relationship to stand the constant battling.Ofsted don't bother Ofsteding the council instead spend a day in our lives, ud b shocked	11/13/2019 12:08 PM
102	Speak to parents who have been through the process, don't bother with parent partnership	11/13/2019 12:05 PM
103	Get professional advice at the start of the EHCP journey - I did not and now have a plan that to a lay person seem really robust but the SEND team are citing as reason for not providing special needs care as it does not specifically state that a trained and qualified professional needs to deliver his health care needs.	11/13/2019 11:39 AM
104	Be the best advocate for your child, you know them best and do not be afraid to speak up in professional meetings.	11/13/2019 11:00 AM
105	Get as much evidence from every professional you meet as you may need it to fight for everything your child needs, it a long and arduous journey that just gets harder so be prepared to be challenged and don't give up, you are their only voice. Try follow policies and read the SEND code of practice: 0 to 25 years, it will be your new best friend	11/13/2019 10:55 AM
106	Things do get better, ask lots of questions	11/13/2019 10:44 AM

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107	Don't take NO for an answer. That is the unofficial policy of CBC especially with regard to EHCP assessments. Don't be afraid to go the full way to HM Tribunal if necessary to get what you / your child needs. Also look at SNAP and Sky Badger for independent support.	11/13/2019 9:53 AM
108	Make sure school listen to your concerns. Don't take no for an answer.	11/13/2019 9:42 AM
109	Talk to other parents who have gone through it, they will understand and it's such a relief that you are not alone with your emotions and worries	11/13/2019 9:33 AM
110	Fight, fight and keep fighting, I started in 2012 and the 2014 did not transform our lives.	11/13/2019 7:46 AM
111	Fight all the way you know your child better than anyone else and never give up even on the really hard days.	11/12/2019 7:42 PM
112	Be prepared for a battle. Complain to the CCG and CBC know the SEND Code of practice and the law - Sendiass are amazing, look after your own mental health..	11/12/2019 7:23 PM
113	Join Facebook groups they offer more help then the local authority	11/12/2019 7:11 PM
114	get support, educate yourself on legislation, believe in yourself that you know your child, keep fighting,	11/12/2019 6:30 PM
115	Be your own advocate and do lots of research.	11/12/2019 5:44 PM
116	This journey isn't easy but just keep fighting for what you need for your child	11/12/2019 4:10 PM
117	You will have to do everything yourself - thr council will obsuct you every step of the way.	11/12/2019 4:03 PM
118	Keep pushing	11/12/2019 2:02 PM
119	Employ a very knowledgeable sen lawyer if you are financially able other they will put barriers up at every hurdle. Even after the tribunal annihilation of central beds we had to instruct our solicitor to start a judicial review against them for delaying our son to go to his residential school. This had the desired effect as all of a sudden everything was sorted in a few hrs!!	11/12/2019 1:35 PM
120	Brace yourself!	11/12/2019 1:26 PM
121	It may well take the destruction of your own mental health and family before you get the help your child needs - think carefully before you start out, surround yourself with support, negotiate early with employers because you'll need their flexibility around appointments/care needs, and also don't have any expectations of anything. If you have no expectations then you will not end up frustrated, hurt, abandoned, etc.	11/12/2019 1:23 PM
122	Prepare for battle. It's a full time job. Talk to parents who are already in the system. Get lots of legal advice from IPSEA and remind the LA of their legal obligations wherever necessary. Be 'that parent' or your child will not get what they need.	11/12/2019 1:00 PM
123	Be prepared for a long wait	11/12/2019 12:28 PM
124	Look on Facebook for groups as you will have to fight the council for every little thing whilst having no support for you and your family in the meantime.	11/12/2019 12:22 PM
125	Save money so you can get legal people as you will need them.	11/12/2019 11:33 AM

Q23 What is the ethnic background of YOUR CHILD/YOUNG PERSON (Optional)

Answered: 155 Skipped: 1



ANSWER CHOICES	RESPONSES	
White British	87.10%	135
White Irish	0.65%	1
White Traveller	0.65%	1
Gypsy/Roma	0.00%	0
Other White background	1.94%	3

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Asian or Asian British Bangladeshi	0.00%	0
Asian or Asian British Indian	0.65%	1
Asian or Asian British Pakistani	0.65%	1
Asian Other	0.00%	0
Mixed White Asian	0.65%	1
Mixed White and Black African	0.65%	1
Mixed White and Black Caribbean	1.29%	2
Mixed Other	0.65%	1
Black or Black British African	0.00%	0
Black or Black British Caribbean	0.00%	0
Black Other	0.00%	0
Chinese	0.00%	0
Prefer not to say	3.87%	6
Other (please specify)	1.29%	2
TOTAL		155

#	OTHER (PLEASE SPECIFY)	DATE
1	It shouldn't make a difference	11/13/2019 12:08 PM
2	Mother is mixed race, father is whits	11/13/2019 10:44 AM