



INTRODUCTION

(Section 2 – Questions 6 -30)

Background

Calderdale Parents and Carers invited all parent carer members to complete the annual survey asking for comments on their satisfaction with public services in Calderdale, access to information, their wellbeing and the support they received during 2015. The survey was open from January - March 2016. The annual survey was launched in 2012 and conducted again in 2013 and 2014.

Method

Parent carers of children with additional needs or disabilities in Calderdale were invited to complete a survey through an online link directly onto Survey Monkey¹ or using paper questionnaires, which were later entered onto Survey Monkey.

Questions 1-5 were about satisfaction with services provided by the charity Calderdale Parents and Carers, asked for the first time in the 2014 survey. They are presented as a separate report.

Questions 6 to 16 were about support and outcomes and invited qualitative views about public services.

Questions 17 to 19 were about access to information.

¹Survey Monkey is software for conducting surveys online.

Questions 20 to 30 were about parent carer wellbeing.

Question 31 was open for individual comments.

Questions 32 to 40 collected personal data about parent carers and their children and contact details.

Sample size

97 responses were received for the 2015 survey.

This compares to 71 in 2014, 77 families in 2013 and 69 families in 2012. 79 families completed monitoring data (in comparison to 51 families – in 2014); collectively they had 186 children (in comparison to 63 – in 2014).

Of these families, 1 had 4 children with additional needs or disabilities and 1 had 3 children with additional needs or disabilities. 12 had 2 children with additional needs or disabilities.

Key for traffic light system

Analyses of figures are colour-coded to provide a quick-reference summary.

Improvement by 5% or more is represented by **green**.

Worsening by 5% or more is represented by **red**.

Movement by less than 5% (stable) is represented by **amber**.

RESULTS

Question 6

‘I am able to access Social Services support appropriate to my child’s needs’

	2012		2013		2014		2015	
Strongly agree or agree	23	40%	27	43%	18	38%	19	32%
Neither Agree or disagree	10	17%	12	19%	12	26%	14	24%
Disagree or strongly disagree	25	43%	24	38%	17	36%	26	44%
Responded	58		63		47		59	
Comments	39		38		34		43	
No response / NA	11		14		24		19	
Total survey / respondents	69		77		71		78	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 78 SKIPPED = 19

Analysis

2015 in comparison to 2014

Compared to 2014 there has been an overall decrease in satisfaction (-6%) and a significant rise in dissatisfaction (+8%) regarding access to appropriate Social Services support.

Trend over 4 years

Over the four years the survey has operated there has been an overall decrease in satisfaction (-8%). There has been a small rise in dissatisfaction (+1%) regarding access to appropriate Social Services support.

Summary of comments

- 23 comments expressed concerns;
- 11 comments were positive;
- 9 respondents reported never needing or trying to access social services support.

Positive comments

- Access through child development centre (1 respondent);
- Support from CPC including advocacy in order to access the social care support (1 respondent);
- Good quality and efficient review by a social worker during transition to adult services (1 respondent);
- Knowing where to go and who to ask (1 respondent).

Negative comments

- Information and support being inaccessible and not forthcoming (12 respondents);
- Timeliness and having to wait for updates, appointments and responses (4 respondents);
- Respondents not understanding or not knowing what is available (4 respondents);
- Short breaks process and outcomes (3 respondents);
- Lack of support for transition to adult services (2 respondents).

Question 7

'I am able to access health services appropriate to my child's needs'

	2012		2013		2014		2015	
Strongly agree or agree	41	65%	40	59%	33	61%	34	45%
Neither Agree or disagree	10	16%	16	24%	8	15%	19	25%
Disagree or strongly disagree	12	19%	12	18%	13	24%	23	30%
Responded	63		68		54		76	
Comments	36		35		17		47	
No response / NA	6		9		17		3	
Total survey / respondents	69		77		71		79	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 79 SKIPPED = 18

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a substantial overall decrease in satisfaction (-16%) and a rise in dissatisfaction (+6%) regarding access to appropriate health services.

Trend over 4 years

Over the four years the survey has operated there has been a marked overall decrease in satisfaction (-20%) and a substantial rise in dissatisfaction (+11%) regarding access to appropriate health services.

Summary of comments

- 21 respondents made positive comments;
- 20 comments were critical.

Positive comments

- Having in place all the relevant services and finding them to be helpful (13 respondents);
- Good relationships with family GPs and finding their help to be accessible (7 respondents);
- Specific mention of positive experiences with Consultants (6 respondents), School Nurse (1 respondent), Cochlear Implant Service (1 respondent), Audiology (1 respondent), Occupational Therapy (1 respondent), Physiotherapy (1 respondent), Speech and Language Therapy (1 respondent), Dietician (1 respondent).

Negative comments

- Services being unavailable or inaccessible due to criteria (9 respondents, 1 of whom felt this amounted to discrimination);
- Delays and waiting lists, and having to chase services (9 respondents);
- Services being too quick to discharge (2 respondents);
- Frustrations with the process of trying to get a diagnosis (2 respondents);
- Not enough communication (2 respondents);
- Specific mention of negative experiences with CAMHS (6 respondents), Consultants (2 respondents), Occupational Therapy (2 respondents), Educational Psychology (1 respondent), Speech and Language Therapy (1 respondent).

Question 8

'I am able to access education resources and support (including home to school transport) appropriate to my child's needs'

	2012		2013		2014		2015	
Strongly agree or agree	39	66%	38	58%	32	59%	40	62%
Neither Agree or disagree	13	22%	14	21%	8	15%	8	12%
Disagree or strongly disagree	7	12%	14	21%	14	26%	17	26%
Responded	59		66		54		65	
Comments	37		34		25		41	
No response / NA	10		11		17		15	
Total survey / respondents	69		77		71		80	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 80 SKIPPED = 17

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a small increase for satisfaction (+3%) and no change in dissatisfaction (0% change) regarding access to appropriate education resources and support.

Trend over 4 years

Over the four years the survey has operated there has been a small overall decrease in satisfaction (-4%), but a substantial rise in dissatisfaction (+14%) regarding access to appropriate education resources and support.

Summary of comments

- 19 respondents expressed negative feedback regarding education;

- 18 respondents were positive about their experiences with educational support, 4 specifically commenting on school transport services.

Positive comments

- Getting plenty of support, including 1:1 (11 respondents);
- Transport staff being friendly and helpful (4 respondents);
- Schools communicating well with parents (3 respondents);
- Advice from specialist services helped, including ASD team and Occupational Therapy (2 respondents).

Negative comments

- Not having the support in place that parents felt was needed (9 respondents);
- Needing to fund support or transport themselves due to this (4 respondents);
- Transport being refused (2 respondents);
- Negative experience with the SEN Team, perception that decisions were made based solely upon funding (1 respondent);
- School not taking professional advice (1 respondent).

Question 9

‘Specialist services and equipment for my child are available in a timely way when needed’

	2012		2013		2014		2015	
Strongly agree or agree	19	42%	23	45%	17	43%	23	43%
Neither Agree or disagree	8	18%	14	27%	10	25%	9	17%
Disagree or strongly disagree	18	40%	14	27%	13	33%	21	40%
Responded	45		51		40		53	
Comments	37		26		20		35	
No response / NA	24		26		31		26	
Total survey / respondents	69		77		71		79	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 79 SKIPPED = 18

Analysis

2015 in comparison to 2014

Compared to 2014 there has been no change in satisfaction (0%) but a significant rise in dissatisfaction (+7%) regarding access to specialist services and equipment.

Trend over 4 years

Over the four years the survey has operated there has been a small overall increase in satisfaction (+1%) and no change in dissatisfaction (0%) regarding access to specialist services and equipment.

Summary of comments

- 21 respondents expressed negative experiences;
- 7 respondents made positive comments;

- 6 responded they did not need specialist services or equipment.

Positive comments

- Services and equipment were available appropriate to children's needs (4 respondents);
- Specific reference to positive experiences with Specialist Inclusion Team for ASD (1 respondent), ENT (1 respondent), Audiology (1 respondent), and the sensory room at Jubilee children's centre (1 respondent).

Negative comments

- Support and/or equipment being refused and needing to fight for these (11 respondents);
- Needing to self-fund equipment as a result of this (7 respondents);
- Long waiting lists (5 respondents).

Question 10

'My child and I are involved in decision making about support packages from services which meet our needs'

	2012		2013		2014		2015	
Strongly agree or agree	31	55%	23	38%	24	48%	28	43%
Neither Agree or disagree	11	20%	18	30%	6	12%	17	26%
Disagree or strongly disagree	14	25%	20	33%	20	40%	20	31%
Responded	56		61		50		65	
Comments	27		30		15		38	
No response / NA	13		16		21		13	
Total survey / respondents	69		77		71		78	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 78 SKIPPED = 19

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a significant overall decrease in satisfaction (-5%) however, conversely, there has been a significant decrease in dissatisfaction (-9%) regarding involvement in decision-making.

Trend over 4 years

Over the four years the survey has operated there has been a significant overall decrease in satisfaction (-12%) and a rise in dissatisfaction (+6%) regarding involvement in decision-making.

Summary of comments

- 13 respondents responded negatively;
- 11 respondents felt they were involved, supported and

encouraged to engage with the support package planning.

Positive comments

- Being contacted by services keen to find out the family's views (1 respondent);
- Things explained appropriately to encourage parents' involvement (1 respondent);
- Specific comments about being involved by school (1 respondent), the Youth Offending Team (1 respondent), and in regards to reviewing a support package (1 respondent).

Negative comments

- Being involved but then views not being taken on board (6 respondents);
- Services being refused or reduced, against families' expressed wishes (4 respondents);
- Specific references to short breaks panel making decisions without family views (3 respondents).

Question 11

‘I can access childcare for my child with disabilities or additional needs which meets our family’s needs’

	2012		2013		2014		2015	
Strongly agree or agree	22	45%	18	38%	13	31%	15	30%
Neither Agree or disagree	10	20%	6	13%	9	21%	12	24%
Disagree or strongly disagree	17	35%	24	50%	20	48%	23	46%
Responded	49		48		42		50	
Comments	31		31		22		34	
No response / NA	20		29		29		30	
Total survey / respondents	69		77		71		80	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 80 SKIPPED = 17

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a small decrease (-1%) in satisfaction and, conversely, a small decrease in dissatisfaction (-2%) regarding access to childcare.

Trend over 4 years

Over the four years the survey has operated there has been a significant overall decrease in satisfaction (-15%) and a significant rise in dissatisfaction (+11%) regarding access to childcare.

Summary of comments

- 13 respondents reported negative experiences with trying to access appropriate childcare;
- 10 respondents gave positive experiences of support, advice

- and access to childcare;
- 9 respondents reported not needing childcare for reasons including having adequate family support, due to their children's ages or because they did not feel childminders would be able to meet their children's needs.

Positive comments

- School and nurseries providing the necessary support, including use of DCATCH funding (5 respondents);
- Use of direct payments to meet children's needs (3 respondents);
- Use of holiday club at North Bridge Leisure Centre (1 respondent).

Negative comments

- Feeling that support available is insufficient (13 respondents);
- Respondents being unaware of what support is available in this respect (5 respondents);
- Nursery not being the appropriate environment but being all that was available (1 respondent);
- Family finances being insufficient to fund appropriate childcare (1 respondent).

Question 12

'My child is enabled to access local community activities and has opportunities to make friends where we live'

	2012		2013		2014		2015	
Strongly agree or agree	23	38%	22	35%	17	35%	24	33%
Neither Agree or disagree	18	30%	17	27%	8	16%	23	31%
Disagree or strongly disagree	19	32%	24	38%	24	49%	26	36%
Responded	60		63		49		73	
Comments	35		35		21		42	
No response / NA	9		14		22		8	
Total survey / respondents	69		77		71		81	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 81 SKIPPED = 16

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a small overall decrease in satisfaction (-2%), but conversely, a significant decrease in dissatisfaction (-13%) regarding access to local community activities.

Trend over 4 years

Over the four years the survey has operated there has been an overall decrease in satisfaction (-5%) and a small rise in dissatisfaction (+4%) regarding access to local community activities.

Summary of comments

- 21 felt their child was unable to access sufficient local

- community activities;
- 20 respondents gave positive responses, feeling their child was able to access local community activities;
 - In 3 cases, despite opportunities being available children did not access these, for example due to dislike of group environments.

Positive comments

- Use of short breaks to enable this (3 respondents);
- Specific positive references to accessing children's centres (3 respondents), NAS activities (3 respondents), Brownies/Cubs (2 respondents), Mixenden Activity Centre (1 respondent), a deaf club (1 respondent), Linden Brook (1 respondent), Jam Packed Summer activities (1 respondent), Mayfield Trust (1 respondent), SEN art sessions (1 respondent), sessions at CPC (1 respondent), Sports Zone (1 respondent), after school clubs (1 respondent) and swimming (1 respondent).

Negative comments

- Activities were not available in families' local areas (6 respondents);
- Not enough activities for certain ages (5 respondents) - in most of these comments this was due to the child being too young;
- Respondents being unsure of what is available (4 respondents);
- Closure of services (2 respondents);
- Activities not being affordable (2 respondents);
- Negative experiences of trying to access mainstream services (2 respondents), with Health and Safety being given as a reason for refusing a disabled child access in one case.

Question 13

‘My child moved from one setting to another this year. The support we received helped to achieve a successful transition’

	2012		2013		2014		2015	
Strongly agree or agree	16	64%	18	55%	19	63%	12	40%
Neither Agree or disagree	4	16%	7	21%	6	20%	5	17%
Disagree or strongly disagree	5	20%	8	24%	5	17%	13	43%
Responded	25		33		30		30	
Comments	19		18		16		23	
No response / NA	44		44		41		51	
Total survey / respondents	69		77		71		81	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 81 SKIPPED = 16

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a marked overall decrease in satisfaction (-23%) and a marked rise in dissatisfaction (+26%) regarding transitions to new settings.

Trend over 4 years

Over the four years the survey has operated there has been a marked overall decrease in satisfaction (-24%) and a marked rise in dissatisfaction (+23%) regarding transitions to new settings.

Summary of comments

- 13 respondents had some Positive comments about the aspects of transition;
- 9 respondents reported difficulties and / or lack of support

during transitions.

Positive comments

- Schools (2 respondents) and the SEN team (1 respondent) felt to be very helpful;
- Appropriate support in place in the new setting (2 respondents).

Negative comments

- No support being provided by school or other services in order to support a smooth transition (4 respondents);
- Support being insufficient in the new setting (2 respondents), with one school not taking the child's needs into account due to lack of diagnosis;
- Limited choice and control over options for settings (1 respondent);
- Administrative errors experienced during the process (1 respondent).

Question 14

'As a parent or carer of a child with disabilities or additional needs, I find support is available for me. (This includes support from family, friends, or voluntary organisations as well as services.)'

	2012		2013		2014		2015	
Strongly agree or agree	34	52%	40	59%	31	56%	34	40%
Neither Agree or disagree	17	26%	9	13%	14	25%	23	17%
Disagree or strongly disagree	15	23%	19	28%	10	18%	22	43%
Responded	66		68		55		79	
Comments	35		33		21		45	
No response / NA	3		9		16		1	
Total survey / respondents	69		77		71		80	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 80 SKIPPED = 17

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a significant overall decrease in satisfaction (-16%) and a marked rise in dissatisfaction (+25%) regarding availability of support.

Trend over 4 years

Over the four years the survey has operated there has been a significant decrease in satisfaction (-12%) and a marked rise in dissatisfaction (+20%) regarding availability of support.

Summary of comments

- 35 respondents reported a range of positive experiences;

- 20 respondents reported negative experiences regarding availability of support;
- 1 respondent reported no need for support.

Positive comments

- Support being available from family and friends was a significant trend (15 respondents);
- Support from other parents (2 respondents);
- Specific positive reference to CPC (7 respondents), Home start (2 respondents), health services (1 respondent), school (1 respondent), Family Support (1 respondent), SENDIASS (1 respondent), NAS (1 respondent), care provider (1 respondent) and Brownies (1 respondent).

Negative comments

- Lack of support from schools, Social services and health (13 respondents);
- Loneliness and isolation being an issue (3 respondents);
- Services provided but not meeting needs (3 respondents);
- Waiting times for support (2 respondents);
- Exhaustion being an issue (1 respondent).

Question 15

‘I know where to find out information about “Calderdale’s Local Offer” for children with special educational needs and disabilities’

	2014		2015	
Strongly agree or agree	30	53%	42	52.5%
Neither Agree or disagree	5	9%	12	15%
Disagree or strongly disagree	22	39%	26	32.5%
Responded	57		80	
No Comment option	--		--	
No response / NA	14		0	
Total survey / respondents	71		80	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 80 SKIPPED = 17

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a small decrease in knowledge (-0.5%) but conversely, a decrease in lack of knowledge (-6.5%) regarding where to find out about the local offer.

Question 16

'I know how to get help and support if I am not satisfied with the support my child gets from their school/setting or Calderdale'

	2014		2015	
Strongly agree or agree	31	53%	40	51%
Neither Agree or disagree	13	22%	11	14%
Disagree or strongly disagree	14	24%	28	35%
Responded	58		79	
No Comment option	--		--	
No response / NA	13		0	
Total survey / respondents	71		80	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 79 SKIPPED = 18

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a small decrease in knowledge (-2%), and a significant rise in lack of knowledge (+11%) regarding where to get support.

Question 17

'I find information about services and other support readily available and accessible'

	2012		2013		2014		2015	
Strongly agree or agree	22	34%	27	39%	19	35%	28	35%
Neither Agree or disagree	26	40%	24	35%	18	33%	19	24%
Disagree or strongly disagree	17	26%	18	26%	17	31%	32	41%
Responded	65		69		54		79	
Comments	30		26		13		39	
No response / NA	4		8		17		1	
Total survey / respondents	69		77		71		80	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 80 SKIPPED = 17

Analysis

2015 in comparison to 2014

Compared to 2014 there has been no change in satisfaction (0%) but a significant rise in dissatisfaction (10%) regarding information being readily available and accessible.

Trend over 4 years

Over the four years the survey has operated there has been a small overall increase in satisfaction (+1%) but a significant rise in dissatisfaction (+15%) regarding information being readily available and accessible.

Summary of comments

- 23 respondents reported not finding information to be readily available and accessible;

- 23 respondents reported positive experiences.

Positive comments

- Word of mouth (12 respondents), with specific mention of information coming via CPC staff (4 respondents), other parents (3 respondents) and a support worker (1 respondent);
- Information being accessible via the internet (7 respondents);
- CPC providing information online, via the e-bulletin and at the office (2 respondents);
- Specific mention of children's centres (1 respondent) and NAS (1 respondent).

Negative comments

- Difficulties and confusion when trying to access information (9 respondents);
- Only being able to find information if you know where to look (4 respondents);
- Lacking time to do the necessary research (1 respondent);
- Despite being able to find information, services then being unavailable (1 respondent);
- Specific negative mentions of the local offer (2 respondents), Social Care (1 respondent) and direct payments (1 respondent).

Question 18

'Please tell us which of the following you currently use to access information about support for your disabled child and family'

	2012		2013		2014		2015	
Internet	48	72%	54	78%	43	77%	60	75%
CPC Newsletter	55	82%	53	77%	45	80%	65	81%
Facebook & other social media	13	19%	26	26%	33	59%	37	46%
Email Bulletins	28	42%	29	42%	23	41%	38	48%
Family Information Service	6	9%	7	10%	6	11%	5	6%
Professional that works with your family	38	57%	22	32%	22	39%	32	40%
Other	21	31%	13	19%	12	21%	14	18%
Responded	67		69		56		80	
Comments	22		20		7		19	
No Response/ NA	2		8		15		17	
Total survey respondents	69		77		71		97	
<i>Multiple answers possible</i>								

Analysis

CPC Newsletter remains the highest ranking information point for respondents (minimal changes of -1% over 4 years and +1% since 2014).

Internet came in as second (small changes of +3% over 4 years and -2% since 2014).

Email bulletins were ranked as third, growing in popularity in comparison to previous years (+6% over 4 years, +7% since 2014).

Facebook use and social media came in fourth (showing a marked

increase over 4 years [+27%] – but a decrease since 2014 [-13%]).

Seeking information from professionals was ranked fifth (significant decrease over 4 years [-17%], but a slight increase since 2014 [+1%]).

Other was ranked sixth (significant decrease over 4 years [-13%], small decrease over 1 year [-3%]).

Guidance from family information service was ranked last (decrease -3% over 4 years, -5% since 2014).

Summary of comments

- 17 respondents gave positive feedback;
- 4 respondents expressed negative experiences.

Positive comments

- Other parents (6 respondents);
- Information sessions and courses (2 respondents);
- Internet (2 respondents);
- Posters (2 respondents);
- Facebook (2 respondents);
- Specific mentions of CPC (4 respondents), school (3 respondents), Contact a Family (1 respondent), SENDIASS (1 respondent).

Negative comments

- Lack of dedicated time to access information / support (1 respondent);
- Not being able to find the information required, specifically a support group for parents of ADHD children (1 respondent);

- Lack of support from professionals in finding information (1 respondent).

Question 19

'Please tell us your preferred form for receiving information'

	2012		2013		2014		2015	
Internet	20	30%	23	33%	21	38%	26	32%
Email Bulletins	58	87%	56	81%	37	67%	71	89%
Facebook & other social media	7	10%	18	26%	19	35%	24	30%
Face to face	31	46%	22	32%	13	24%	24	30%
Phone	17	25%	14	20%	13	24%	16	20%
Post	30	45%	28	41%	18	33%	28	35%
Other	2	3%	3	4%	1	2%	0	0%
Responded	67		69		55		80	
No Option for Comments								
No Response/ NA	2		8		16		17	
Total survey respondents	69		77		71		97	
<i>Multiple answers possible</i>								

Analysis

E-bulletins were ranked as the most preferred form of receiving information (Small increase of +2% in 4 years, marked increase of +22% since 2014).

Post was ranked second choice (significant decrease of -10% in 4 years, but a small increase of +2% since 2014).

The internet came in third (small increase of +2% in 4 years, decrease of -6% since 2014).

Facebook and social media (significant increase of +20% in 4 years, decrease of -5% since 2014) came in at joint fourth with face-to-face (significant decrease in 4 years of -16%, increase of +6% since 2014).

Phone was ranked fifth (Decrease of -5% in 4 years, decrease of -4% since 2014).

Other was ranked as last (decrease of -3% in 4 years, decrease of -2% since 2014).

Question 20

'I am able to maintain my own life and identity over and above being the parent of a disabled child'

	2012		2013		2014		2015	
Strongly agree or agree	19	31%	26	38%	25	47%	29	37%
Neither Agree or disagree	22	35%	11	16%	9	17%	28	35%
Disagree or strongly disagree	21	34%	31	45%	19	36%	22	28%
Responded	62		68		53		79	
Comments	31		34		22		1	
No response / NA	7		9		18		0	
Total survey / respondents	69		77		71		79	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 79 SKIPPED = 18

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a significant overall decrease in satisfaction (-10%) but a significant decrease in dissatisfaction (-8%) regarding maintaining one's own life and identity.

Trend over 4 years

Over the four years the survey has operated there has been an overall increase in satisfaction (+6%) and decrease in dissatisfaction (-6%) regarding maintaining one's own life and identity.

Summary of comments

- 34 respondents expressed difficulties and issues in regards to this statement;

- 15 respondents reported they were able to maintain their own life and identity, although most (11) added that this was with great effort.

Positive comments

- Supportive family and friends (2 respondents);
- Employment (2 respondents);
- CPC (2 respondents);
- Returning to study (1 respondent);
- Having time whilst the child is at school (1 respondent);
- Having the right support in place to enable this (1 respondent).

Negative comments

- Life revolving around the child's needs (13 respondent);
- Effects on carers' wellbeing including loneliness, exhaustion, depression and anxiety (8 respondents);
- Lacking a social life or opportunities for holidays and days out (6 respondents);
- Difficulties in maintaining employment (3 respondents);
- Effects on family relationships (2 respondents);
- Feeling of guilt for taking time for oneself (1 respondent);
- Specific negative mention of school (1 respondent) and CAMHS (1 respondent).

Question 21

‘I am able to maintain a balance between caring for my disabled child and spending quality time with my disabled child’

	2012		2013		2014		2015	
Strongly agree or agree	26	43%	30	45%	31	66%	30	40%
Neither Agree or disagree	21	35%	18	27%	7	15%	27	35%
Disagree or strongly disagree	13	22%	18	27%	9	19%	19	25%
Responded	60		66		47		76	
Comments	21		23		12		30	
No response / NA	9		11		24		3	
Total survey / respondents	69		77		71		79	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 79 SKIPPED = 18

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a marked decrease in satisfaction (-26%) and a rise in dissatisfaction (+6%) regarding ability to maintain a balance.

Trend over 4 years

Over the four years the survey has operated there has been a small overall decrease in satisfaction (-3%) and a small rise in dissatisfaction (+3%) regarding ability to maintain a balance.

Summary of comments

- 18 respondents gave negative responses;
- 18 respondents gave a positive response.

Positive comments

- Finding time to take part in activities such as going to the cinema and swimming (5 respondents);
- Helping the child with homework (1 respondent);
- Being able to go on family holidays (1 respondent).

Negative comments

- Being too tired and stressed, needing to use the time away from caring to recuperate (4 respondents);
- Finding it hard to differentiate between caring and quality time (1 respondent);
- Quality time being at the expense of housework (1 respondent);
- Employment reducing the opportunity for quality time (1 respondent);
- No support from services to encourage quality time (1 respondent).

Question 22

‘We are able to maintain family life and undertake activities together’

	2012		2013		2014		2015	
Strongly agree or agree	25	40%	29	42%	29	54%	29	37%
Neither Agree or disagree	18	29%	18	26%	8	15%	27	34%
Disagree or strongly disagree	19	31%	22	32%	17	31%	23	29%
Responded	62		69		54		79	
Comments	29		30		15		37	
No response / NA	7		7		17		1	
Total survey / respondents	69		77		71		80	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 80 SKIPPED = 17

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a significant overall decrease in satisfaction (-17%) but a small decrease in dissatisfaction (-2%) regarding maintaining family life.

Trend over 4 years

Over the four years the survey has operated there has been a small overall decrease in satisfaction (-3%) but a small decrease in dissatisfaction (-2%) regarding maintaining family life.

Summary of comments

- 27 respondents reported difficulties in this area;
- 17 respondents recorded being able to maintain family life, however 7 of those added that this is not easy.

Positive comments

- Being able to attend activities as a family, including walks, museums, bowling and the cinema (2 respondents);
- Having a routine for family time (1 respondent);
- Planning trips in line with the disabled child's needs (1 respondent).

Negative comments

- Needing to separate family members, including separating siblings, due to the child's needs, aggression or fighting (5 respondents);
- The weather affecting the ability of the whole family to go out (3 respondents), e.g. due to the disabled child getting infections in winter;
- Family holidays being impossible or difficult (2 respondents);
- Family trips being difficult or stressful (2 respondents).

Question 23

I am able to maintain relationships with family and friends'

	2012		2013		2014		2015	
Strongly agree or agree	25	42%	29	41%	28	51%	31	39%
Neither Agree or disagree	16	27%	22	31%	9	16%	29	36%
Disagree or strongly disagree	19	32%	19	27%	18	33%	20	25%
Responded	60		70		55		80	
Comments	26		23		13		35	
No response / NA	9		7		16		0	
Total survey / respondents	69		77		71		80	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 80 SKIPPED = 17

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a significant overall decrease in satisfaction (-12%) but conversely, a significant decrease in dissatisfaction (-8%) regarding maintaining relationships.

Trend over 4 years

Over the four years the survey has operated there has been a small overall decrease in satisfaction (-3%) but conversely, a significant decrease in dissatisfaction (-7%) regarding maintaining relationships.

Summary of comments

- 20 respondents gave negative responses;
- 17 respondents gave positive responses.

Positive comments

- Family and friends being a vital support system (5 respondents);
- Friendships with other parent carers (3 respondents);
- Finding time during school hours (1 respondent).

Negative comments

- Lack of understanding from friends and family impacting negatively on the relationship (8 respondents);
- Having no time or energy for friends and family (4 respondents);
- Finding it hard to commit to plans due to the child's needs being unpredictable (1 respondent).

Question 24

'I feel confident in the services and professionals who work with us'

	2012		2013		2014		2015	
Strongly agree or agree	33	53%	34	52%	33	62%	30	38%
Neither Agree or disagree	20	32%	15	23%	12	23%	27	35%
Disagree or strongly disagree	9	15%	17	26%	8	15%	21	27%
Responded	62		66		53		78	
Comments	28		21		15		34	
No response / NA	7		11		18		2	
Total survey / respondents	69		77		71		80	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 80 SKIPPED = 17

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a marked overall decrease in satisfaction (-24%) and a significant rise in dissatisfaction (+12%) regarding confidence in services and professionals.

Trend over 4 years

Over the four years the survey has operated there has been a significant overall decrease in satisfaction (-15%) and a significant rise in dissatisfaction (+12%) regarding confidence in services and professionals.

Summary of comments

- 26 respondents had negative experiences or opinions of interaction with professionals;

- 21 respondents had positive experiences to share.

Positive comments

- Support received from school (5 respondents);
- Support received from CPC (4 respondents);
- Specific mention also of Home start (1 respondent), the ASD team (1 respondent), SENDIASS (1 respondent), NAS (1 respondent) and private services (1 respondent).

Negative comments

- Support not being suited to the needs of the family and needing to take tasks on themselves (4 respondents);
- Schools not being supportive (4 respondents);
- Professionals leaving services (3 respondents);
- Long waiting times (2 respondents);
- Feeling like professionals have all the answers and children have to fit in with their systems (1 respondent);
- Receiving conflicting information (1 respondent);
- Being required to pay for private services due to lack of support (1 respondent);
- Specific negative mention of Local Authority services (2 respondents), health services (2 respondents, one specifically referring to CAMHS), Family Support (1 respondent) and a support worker (1 respondent).

Question 25

'I am able to regularly get a good night's sleep'

	2012		2013		2014		2015	
Strongly agree or agree	28	44%	29	43%	25	45%	35	45%
Neither Agree or disagree	9	14%	11	16%	7	13%	16	20%
Disagree or strongly disagree	26	41%	27	40%	23	42%	27	35%
Responded	63		67		55		78	
Comments	25		26		12		36	
No response / NA	4		10		16		1	
Total survey / respondents	69		77		71		79	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 79 SKIPPED = 18

Analysis

2015 in comparison to 2014

Compared to 2014 there has been no change in satisfaction (0%) and a significant decrease in dissatisfaction (-7%) regarding ability to get a good night's sleep.

Trend over 4 years

Over the four years the survey has operated there has been a small increase in satisfaction (+1%) and a decrease in dissatisfaction (-6%) regarding ability to get a good night's sleep.

Summary of comments

- 28 respondents reported having issues with getting regular, quality sleep;
- 15 respondents reported being able to get some quality sleep some or all of the time, however 2 respondents highlighted this was the result of a lot of work.

Positive comments

- Melatonin prescriptions (3 respondents);
- The parent themselves taking medication (2 respondents);
- Being so worn out from daytime caring duties that sleeping at night is easy (1 respondent).

Negative comments

- Child having care needs during the night, or the child's own sleeping difficulties (16 respondents);
- Parents' own stress and anxiety keeping them awake at night (4 respondents).

Question 26

'I regularly feel stressed'

	2012		2013		2014		2015	
Strongly agree or agree	33	52%	35	51%	29	54%	38	49%
Neither Agree or disagree	16	25%	17	25%	7	13%	19	24%
Disagree or strongly disagree	14	22%	16	24%	18	33%	21	27%
Responded	63		68		55		78	
Comments	22		24		15		36	
No response / NA	6		9		17		1	
Total survey / respondents	69		77		71		80	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 79 SKIPPED = 18

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a decrease in feeling stressed (-5%) but conversely a decrease in not feeling stressed (-6%).

Trend over 4 years

Over the four years the survey has operated there has been a small overall decrease in feeling stressed (-3%) and a rise in not feeling stressed (+5%).

Summary of comments

- 31 respondents reported undergoing some distinct degree of stress;
- 10 respondents reported having no stress, or being able to manage this effectively.

Positive comments

- Managing stress via exercise and improved diet (1 respondent);
- Managing stress with support from services such as befriending, and training (1 respondent).

Negative comments

- The child having substantial needs requiring high levels of support and vigilance (14 respondents);
- Worrying about work (8 respondents), including the task of juggling this with caring;
- Stress as a result of services (5 respondents) e.g. battles for support);
- Financial worries (3 respondents);
- Worry about the child finding employment (1 respondent).

Question 27

'I am able to take time to look after my own physical health'

	2012		2013		2014		2015	
Strongly agree or agree	22	34%	22	31%	24	44%	23	29%
Neither Agree or disagree	20	31%	18	26%	12	22%	26	33%
Disagree or strongly disagree	22	34%	30	43%	19	35%	30	38%
Responded	64		70		55		79	
Comments	23		23		10		31	
No response / NA	5		7		16		1	
Total survey / respondents	69		77		71		80	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 80 SKIPPED = 17

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a significant overall decrease in satisfaction (-15%) and a small rise in dissatisfaction (+3%) regarding having time to look after one's own physical health.

Trend over 4 years

Over the four years the survey has operated there has been a decrease in satisfaction (-5%) and a small rise in dissatisfaction (+4%) regarding having time to look after one's own physical health.

Summary of comments

- 21 respondents gave negative responses;
- 18 respondents gave positive responses.

Positive comments

- Finding time to exercise (8 respondents) including walking, running and going to the gym;
- Attending a slimming club (1 respondent);
- Eating a healthy diet (1 respondent);
- Having good support from family to enable this (1 respondent).

Negative comments

- Not attending health appointments for oneself due to the child's needs or conflicting appointments (3 respondents);
- Problems arising, worsening or not improving as a result of the caring role (3 respondents).

Question 28

'I am able to take a break from caring responsibilities'

	2012		2013		2014		2015	
Strongly agree or agree	19	30%	20	29%	28	51%	33	42%
Neither Agree or disagree	17	27%	16	24%	18	15%	19	25%
Disagree or strongly disagree	27	43%	32	47%	19	35%	26	33%
Responded	63		68		55		78	
Comments	29		27		16		34	
No response / NA	6		9		16		1	
Total survey / respondents	69		77		71		79	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 79 SKIPPED = 18

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a significant overall decrease in satisfaction (-9%) but a small decrease in dissatisfaction (-2%) regarding ability to take a break.

Trend over 4 years

Over the four years the survey has operated there has been a significant overall increase in satisfaction (+12%) and a significant decrease in dissatisfaction (-10%) regarding ability to take a break.

Summary of comments

- 21 respondents gave positive responses;
- 18 respondents gave negative responses.

Positive comments

- Having good levels of support from family and friends (10 respondents);
- Getting a break during school hours (5 respondents);
- Direct payments (2 respondents);
- Getting a break while the child is at cubs (1 respondent);
- The child having independence skills, such as cooking (1 respondent).

Negative comments

- Being unable to leave the child alone or with others due to their level of need (4 respondents);
- Reducing work hours in order to get a break (1 respondent);
- Dreading school pick-up time (1 respondent);
- Using any break to organise things for the child (1 respondent).

Question 29

'I feel worried about my child's safety and/or my family's safety

	2012		2013		2014		2015	
Strongly agree or agree	22	37%	35	52%	19	39%	35	47%
Neither Agree or disagree	15	25%	15	22%	16	33%	12	16%
Disagree or strongly disagree	22	37%	17	25%	14	29%	28	37%
Responded	59		67		49		75	
Comments	23		22		12		29	
No response / NA	10		10		22		3	
Total survey / respondents	69		77		71		78	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 78 SKIPPED = 19

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a significant overall increase in worry (+8%) but conversely, a significant rise in not feeling worried (+10%).

Trend over 4 years

Over the four years the survey has operated there has been an overall increase in worry (+8%) and no change in not feeling worried (0%).

Summary of comments

- 24 respondents reported negative experiences;
- 6 respondents gave positive responses.

Positive comments

- Medication helping with the child's behavior (1 respondent).

Negative comments

- Behaviour of the child leading to risks to self and others (11 respondents);
- Children having no sense of danger (6 respondents);
- Worrying about what the future holds (5 respondents);
- Being unable to access training and/or support in the way of short breaks (2 respondents);
- The child being unable to tell someone about risk (1 respondent);
- Risks with internet use (1 respondent);
- Risks with travel (1 respondent);
- Worry about the child being taken advantage of (1 respondent);
- School having a lack of understanding (1 respondent);
- Police involvement as a result of the child's behaviour (1 respondent).

Question 30

'I feel that my family is able to manage financially'

	2012		2013		2014		2015	
Strongly agree or agree	27	45%	31	45%	28	52%	36	48%
Neither Agree or disagree	23	38%	23	33%	13	24%	25	33%
Disagree or strongly disagree	10	17%	15	22%	13	24%	14	19%
Responded	60		69		54		75	
Comments	17		19		10		26	
No response / NA	9		8		17		3	
Total survey / respondents	69		77		71		78	

NB – 2015 - TOTAL RESPONDENTS = 97 QUESTION RESPONDENTS = 78 SKIPPED = 19

Analysis

2015 in comparison to 2014

Compared to 2014 there has been a small decrease in satisfaction (-4%) but conversely, a decrease in dissatisfaction (-5%) regarding ability to manage financially.

Trend over 4 years

Over the four years the survey has operated there has been a small overall increase in satisfaction (+3%) but a small rise in dissatisfaction (+2%) regarding ability to manage financially.

Summary of comments

- 18 respondents reported feeling able to manage, however 9 of these added that this was hard or had worries about sustaining this;
- 14 respondents gave negative responses.

Positive comments

- Budgeting well (4 respondents);
- Working (3 respondents);
- Use of DLA and Carer's Allowance (2 respondents);
- Having supportive family (1 respondent);
- Feeling informed by CPC about support available (1 respondent).

Negative comments

- Financial demands of having a disabled child in the way of equipment, therapy, adaptations and replacing items broken through the child's behavior (3 respondents);
- Being unable to work due to the child's needs (2 respondents);
- Having debt (1 respondent);
- Having to jump through hoops to get financial support (1 respondent);
- High stress levels resulting from financial struggles (1 respondent).

Question 31

Please use this space to tell us anything else you would like to. This information will help us identify key themes and support services to develop in directions that meet people's needs. You might like to tell us about something you need more information about, an experience you have had, either positive or negative, or perhaps a way in which you think a service might be improved.

Summary of comments

- 19 respondents gave negative comments;
- 14 respondents gave positive comments;
- 13 respondents made suggestions for consideration.

Positive comments

- Support received from CPC (7 respondents);
- Support from Portage (1 respondent);
- Positive experience of education (1 respondent);
- Improved quality of life for the family due to support (1 respondent).

Negative comments

- Not having the required support, equipment etc. and needing to battle for this (11 respondents);
- Negative experiences of Local Authority support (3 respondents);
- Negative experiences of therapy services including OT and Physiotherapy (3 respondents);
- Lacking knowledge of what is available (2 respondents);
- CPC not involving people from different backgrounds (2 respondents);
- Diagnosis process (2 respondents);

- Worrying about the future (2 respondents);
- Services having a lack of understanding (1 respondent);
- Isolation (1 respondent);
- School (1 respondent);
- Changes of staff at CPC (1 respondent).

Suggestions made

- More information should be provided for parents (5 respondents) including specific requests for information on behavior and anxiety;
- Services should be better promoted and information forthcoming so that parents know what they can access (3 respondents);
- CPC should provide more activities (2 respondents);
- There should be more specific support groups (2 respondents);
- Services should communicate better with each other (2 respondents);
- CPC should ensure that parents whose first language is not English are supported adequately (2 respondents);
- A keyworker would be helpful (1 respondent);
- More help is needed for transitions (1 respondent);
- More support with transport is needed (1 respondent);
- Training for schools would help them to better support disabled children (1 respondent);
- Support is needed based closer to home for those not based in Halifax (1 respondent).