



State of Sheffield 2019



**The views of parents of
children and young people
(aged 0-25 years)
with special educational
needs and/or disabilities**

March 2019

Full report

About Sheffield Parent Carer Forum

Sheffield Parent Carer Forum is a parent-led charity which brings together almost 1,800 families with disabled children and young people (aged 0-25 years) from across Sheffield to provide mutual support, share information and influence policy and practice.

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Acknowledgements

We would like to thank the families who told us about their experiences.

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1. Introduction

This report summarises a survey of the views and experiences of parents of children and young people (aged 0-25 years) with special educational needs and/or disabilities (SEND) in Sheffield.

The survey was carried out by Sheffield Parent Carer Forum (SPCF) between November 2018 and January 2019 with funding from the Department for Education's Parent Participation Grant.

The survey aimed to:

- gather data on issues raised by parent carers;
- find out how caring for a child with SEND affects the whole family;
- compare current levels of parental satisfaction with local services with baseline data gathered in 2014, to assess the impact of the Children and Families Act 2014 and the Care Act 2014.

The findings and recommendations will be presented to Sheffield City Council, NHS Sheffield Clinical Commissioning Group and relevant providers of education, health and social care services. SPCF will work with them to address the key issues identified in this report.

In particular, SPCF will work to ensure that findings from this survey inform the Written Statement of Action that the local area is required to produce. This must address the areas of significant weakness that were identified by Ofsted and the Care Quality Commission (CQC) during a SEND inspection in November 2018.

Funding permitting, this survey will be repeated periodically to monitor progress.

2. Method and sample

Parents' views were sought through an online questionnaire, which was open for 13 weeks (5 November 2018 to 1 February 2019).

The survey was advertised via SPCF's email list, SMS list, website and social media channels. The link to the survey was circulated to the email list of the Child Disability Register, and we asked local parent support groups to publicise the survey to their members.

In order to increase responses from underrepresented groups, we sent targeted emails to parents of children with primary needs other than autism spectrum disorder (ASD), parents of children aged 0-5 years and 16-25 years, and parents who are non White British. In addition, we asked local BME organisations, Family Centres, special schools with predominantly non-ASD cohorts and further education colleges to publicise the survey to parents. Whilst this did result in an increase in responses from the groups that were targeted, overall responses also continued to increase, negating any significant percentage gains.

A total of **706 responses** were received. This is a significant increase from our 2014 survey, which received 320 responses. The response rate from SPCF members contacted via email or SMS was **39%**.

The questionnaire consisted of 65 open and closed questions, covering nine areas: family life, work and finances, childcare, education, social care, healthcare, transition to adulthood, information and communication, and general issues.

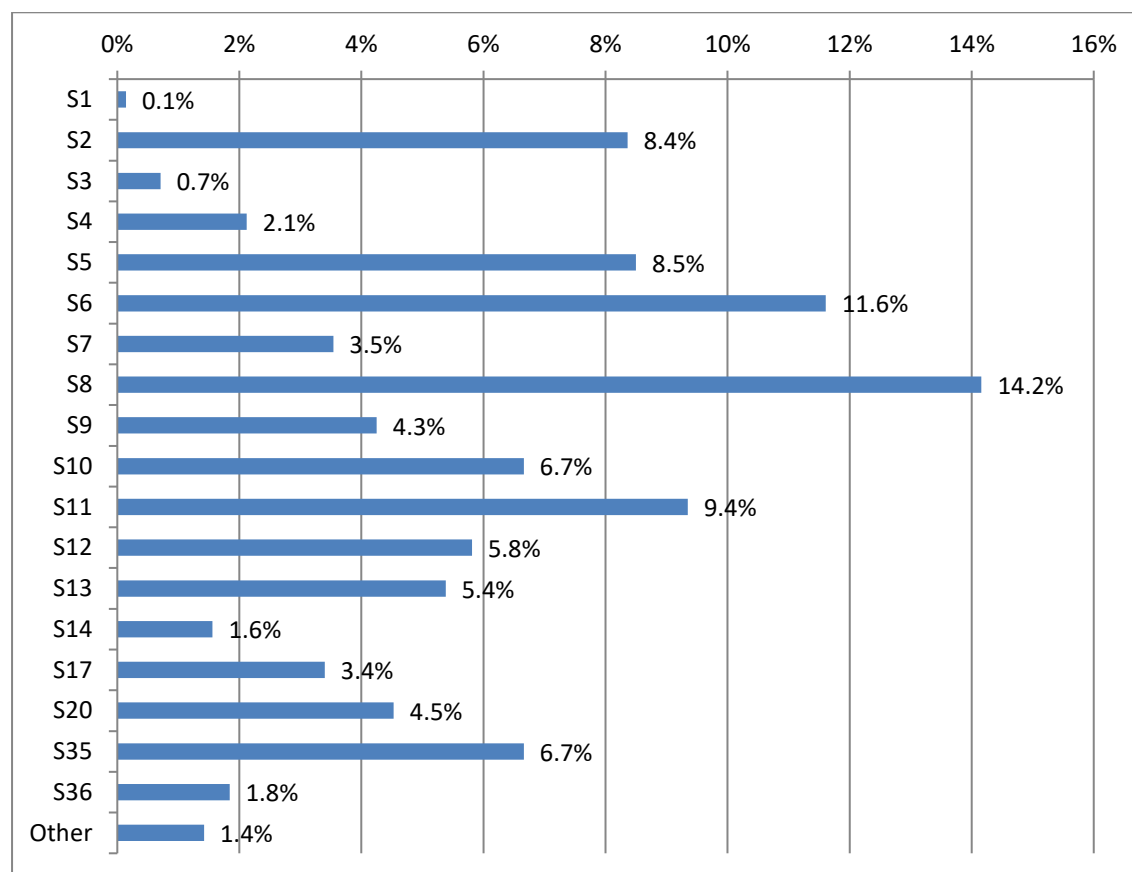
Respondents took an average of 17 minutes to complete the survey. Given the pressures described by the respondents, this may reflect their depth of feeling and need to be heard.

The sample covered the full range of children's impairment types, age groups (0-25 years), educational placements, family situations, and postcode areas (including areas with high levels of economic deprivation). **45%** of respondents were in receipt of means-tested benefits. **15%** were non White British. **52%** of the children in the sample had an EHC plan and **21%** had a My Plan.

3. About our respondents

4.1 Postcode areas (706 responses)

There was a good spread across the city with all postcodes showing a level of representation, including areas with high levels of economic deprivation:



4.2 Gender (706 responses)

92% of respondents were female and **8%** were male.

We find that the pressures associated with raising a disabled child often force parents to assume traditional gender roles, with the father taking on the role of the main breadwinner, and the mother doing most of the day-to-day caring, attending meetings with professionals, and learning to navigate the “system”. This can lead to fathers feeling less informed and less competent, which may affect their willingness to take part in consultations.

4.3 Ethnicity (706 responses)

84.7% of respondents were White British, **14%** belonged to a BME community, and **1.3%** did not state their ethnicity. The biggest BME groups were Pakistani (**3.8%**), Black African (**1.4%**) and Caribbean (**1.3%**).

4.4 Language (695 responses)

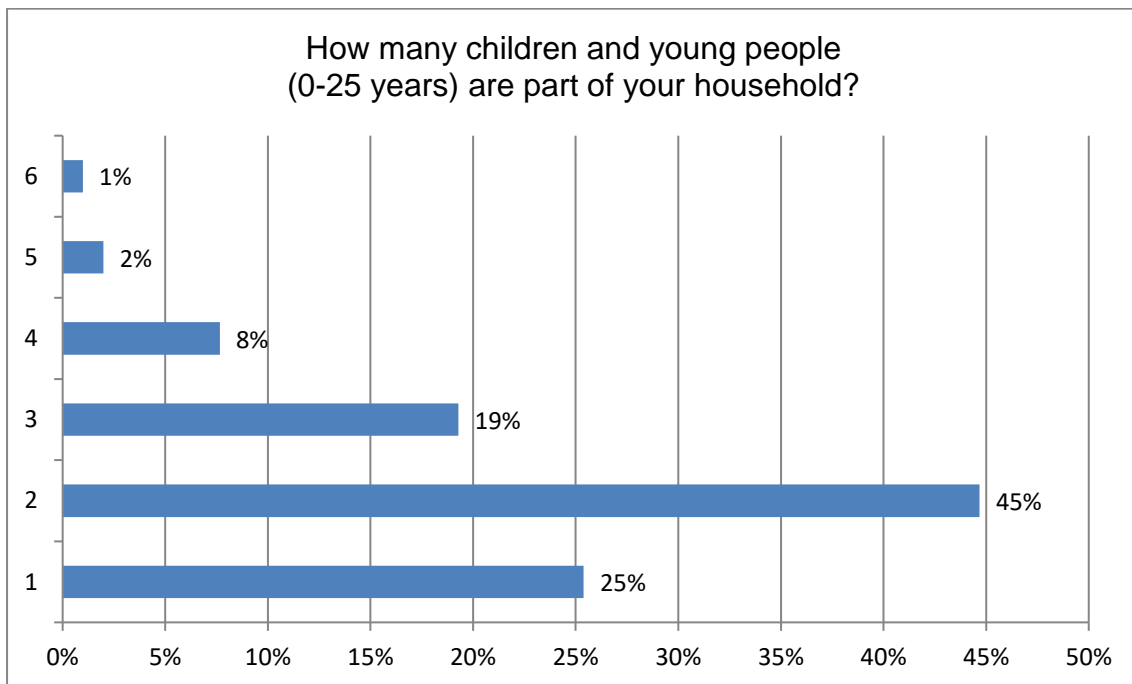
95% of respondents said that English was their first language; **5%** said that it was not.

4.5 Parental disability or illness (697 responses)

19% of respondents said they had a disability or long-term illness themselves.

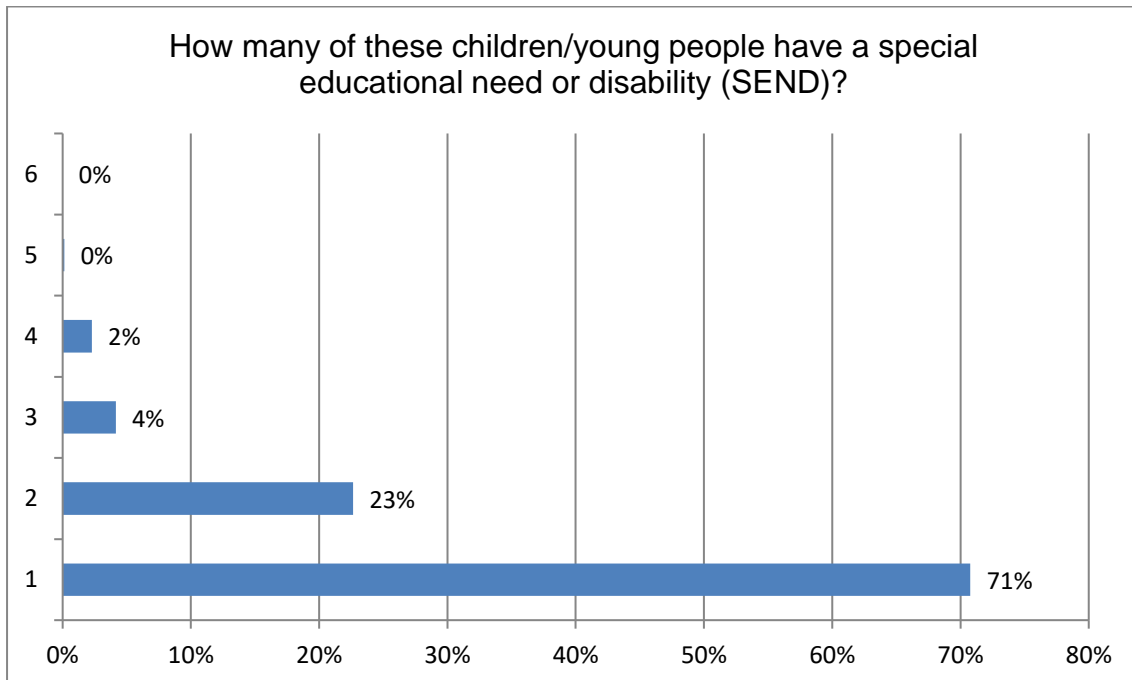
4.6 Number of children and young people in the household (705 responses)

30% of respondents had three or more children or young people living in their household.



4.7 Number of children and young people with SEND (698 responses)

29% of respondents had more than one child with SEND.



4.8 Providing care for an adult aged 25+ (704 responses)

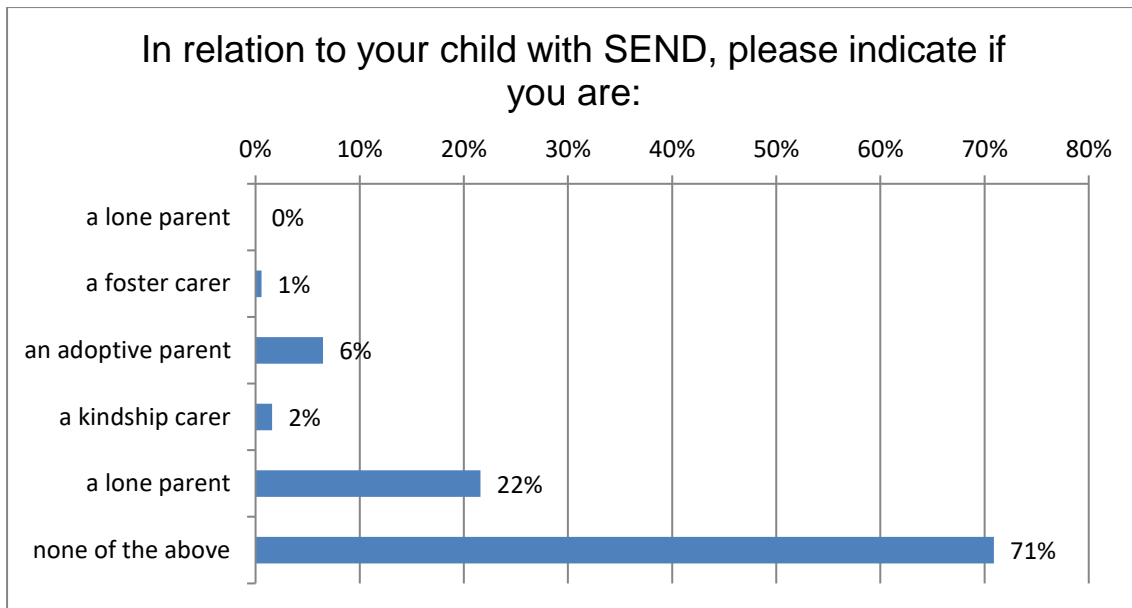
16% of respondents said they also provided care for an adult over the age of 25, such as an elderly parent or a disabled partner.

4.9 Parenting situations (694 responses)

At 22%, the proportion of single-parent families in our sample was slightly lower than the national average (around 25% of all families with dependent children in 2017).

6% of respondents were adoptive parents.

2% of respondents said that they were kinship carers. We know from contact with grandparent carers that this group faces significant barriers to accessing support, particularly social care services and financial support (benefits and grants).



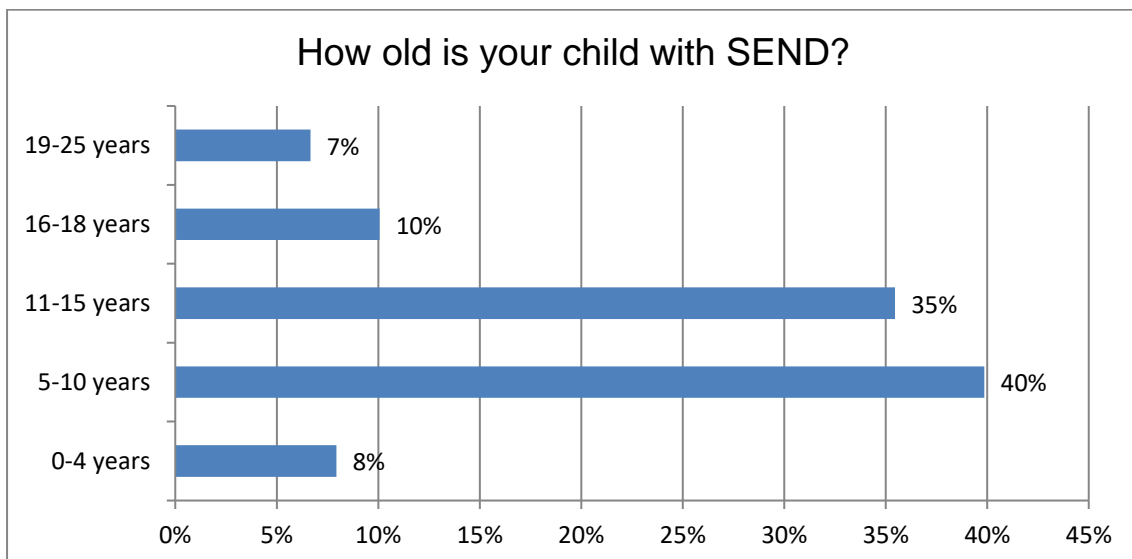
4.10 Sheffield Parent Carer Forum membership (703 responses)

82% of respondents were members of the Sheffield Parent Carer Forum, **18%** were not. This shows that the strategies used to publicise the survey beyond the membership were successful.

The response rate from SPCF members contacted via email or SMS was **39%**.

4.11 Age of child with SEND (705 responses)

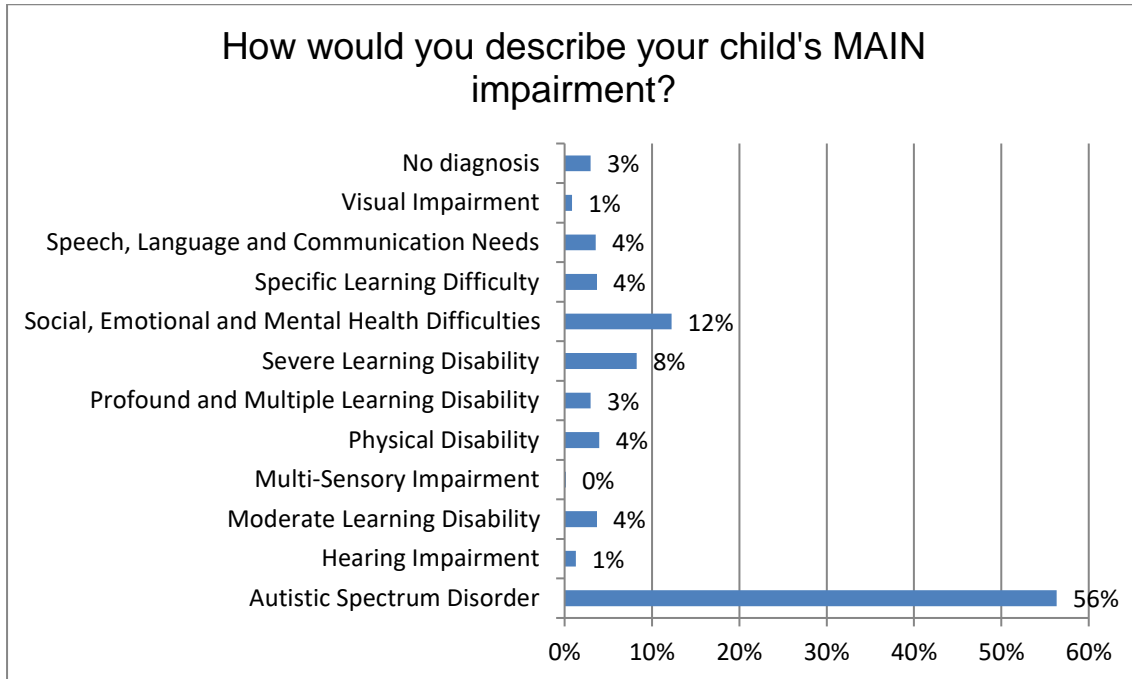
Respondents represented a wide spread of age groups, with a cluster around the 5-15 age group. The underrepresentation of parents of pre-school children may be due to the fact that many children do not receive a formal diagnosis until they enter the school system.



4.12 Impairment type (703 responses)

The survey covered the full range of impairment types. Respondents were asked to select only their child's main impairment.

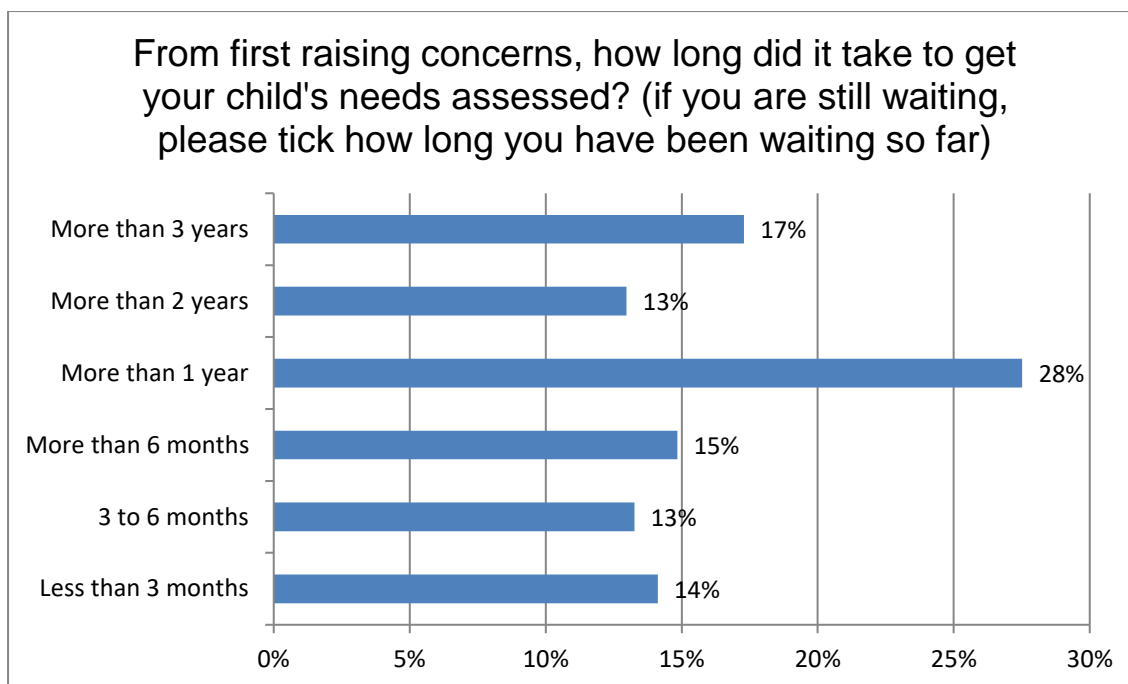
The table below does not reflect the fact that many children have multiple diagnoses. For example, only six respondents listed "Visual Impairment" as their child's main impairment; however, 50 respondents gave feedback on the Vision Support Service.



4.13 Assessment of needs (694 responses)

We asked parents how long it took to get their child's needs assessed. Almost three quarters (**73%**) had waited for more than six months; over half (**58%**) had waited for more than a year, **30%** had waited more than two years, and **17%** had waited more than three years.

NB We did not ask parents how long ago their child was assessed, so this may include pre-2014 data.



When we looked at the families who had waited a year or more to get their child’s needs assessed, we found that children with ASD were overrepresented (**64%** vs **56%** in the total sample).

Families who reported prompt access to assessments (6 months or less) were significantly less likely to report that they were “struggling” or “not coping”, and more likely to say that their child’s educational provision was adequate for meeting their needs.

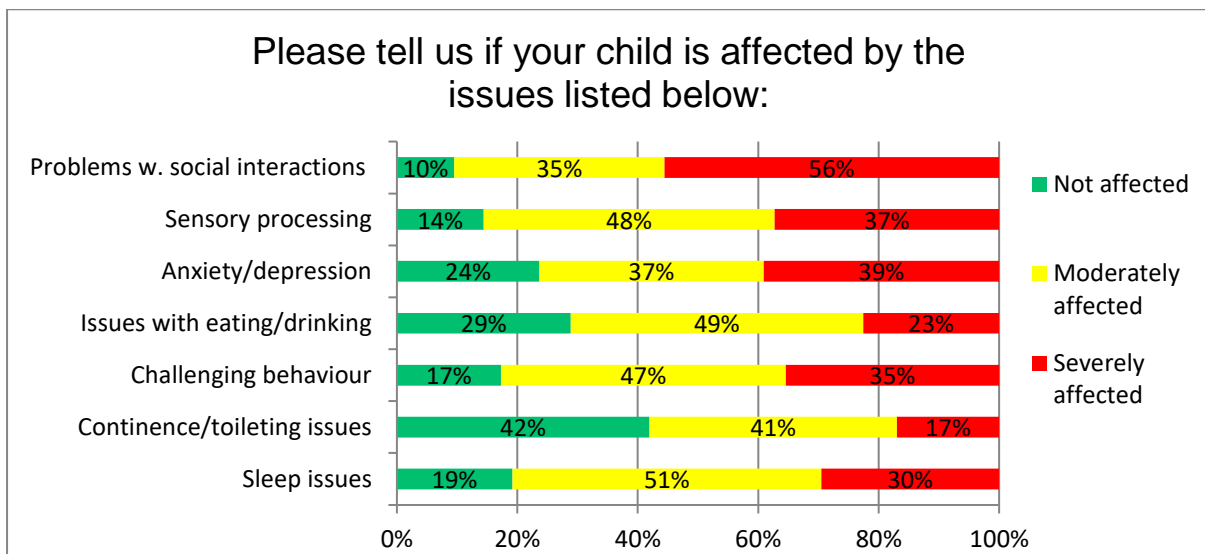
We did not ask parents for free-text comments in this section. However, there were many comments of about difficulties accessing assessments in the section on education:

“My child has developmental language disorder. Despite seeking assessments from age 6 this wasn’t diagnosed until age 9, not a well-known / understood condition. Wish my child had more widely recognised issue e.g. dyslexia, suspect it would be easier to access support.”

“My daughter struggled all throughout primary school with no support and we even had to pay for assessment ourselves as the school wouldn’t listen to us. Both my daughters came out as severely dyslexic with above average IQs. The school had them down as below average ability. It simply isn’t fair how our dyslexic children are treated.”

“School head teacher initially told me it was bad parenting, refused to send letter to GP to request referral to Ryegate.”

4.13 Areas of difficulty (703 responses)



We wanted to find out how a child’s SEND affects them in everyday life. With the exception of continence/toileting issues, all of the problems listed were extremely common, affecting over **two thirds** of the children in the sample. It was also common for children to have difficulties in more than one area. Problems with social interaction affected **90%** of the children in our sample, **86%** struggled with sensory processing difficulties (e.g. oversensitivity to noise or smells, sensory-seeking behaviours, restricted diets due to aversion to food textures), **83%** displayed challenging behaviour, **81%** had sleep issues and **76%** were affected by anxiety and/or depression.

This is significantly more than in our 2014 survey, where **59%** reported problems with challenging behaviour, **53%** with sleep and **43%** with anxiety/depression. (we did not ask about problems with social interactions or sensory processing). However, it should be noted that our previous survey did not offer respondents the option to differentiate between “moderately” and “severely” affected.

4. Family life

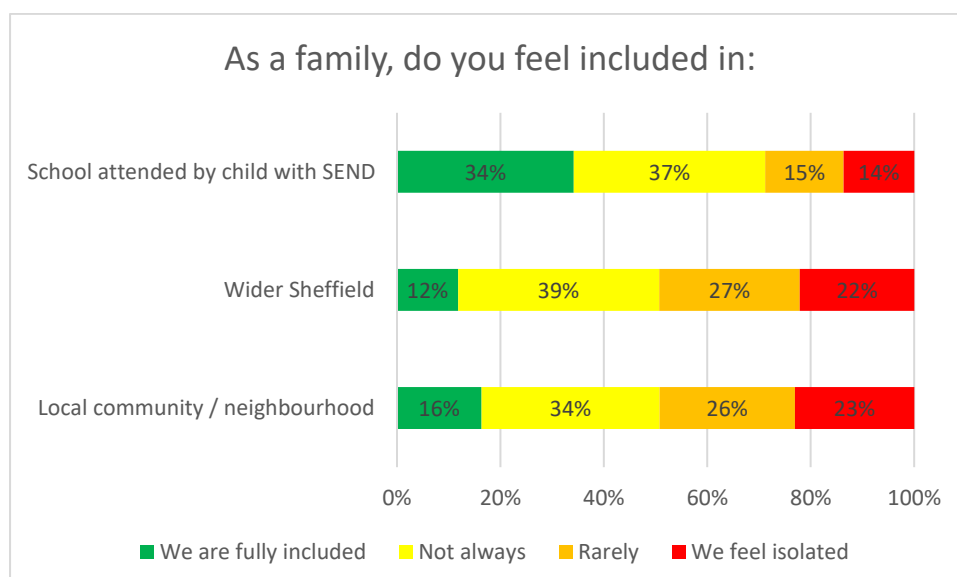
5.1 Doing things together as a family (678 responses)

We asked parents whether caring for a child with SEND restricted what they and/or their family could do together.

Over **60%** of respondents said it was “Difficult”, “Very difficult” or “Impossible” to carry out everyday activities such as visiting friends or family, going out for a meal or to the cinema, taking regular exercise, going out for the day, or going on holiday. Only a minority (between **8%** and **18%**) rated these activities as “Easy”.

5.3 Feeling included (673 responses)

We asked parents whether they felt their family was included in their local community/neighbourhood, wider Sheffield and the school attended by the child with SEND:



A comparison with our 2014 survey shows that levels of isolation have increased. The percentage of parents who felt isolated within their child’s school had increased from **8%** to **14%**. More parents said they felt isolated in their local community (an increase from **16%** to **23%**) and in wider Sheffield (from **16%** to **22%**).

Schools play a vital role in enabling marginalised families to feel part of a community. The level of inclusion varied between school types, with more parents feeling fully included in special schools (**63%**) than in Integrated Resources (**18%**) and in mainstream schools (**23%**).

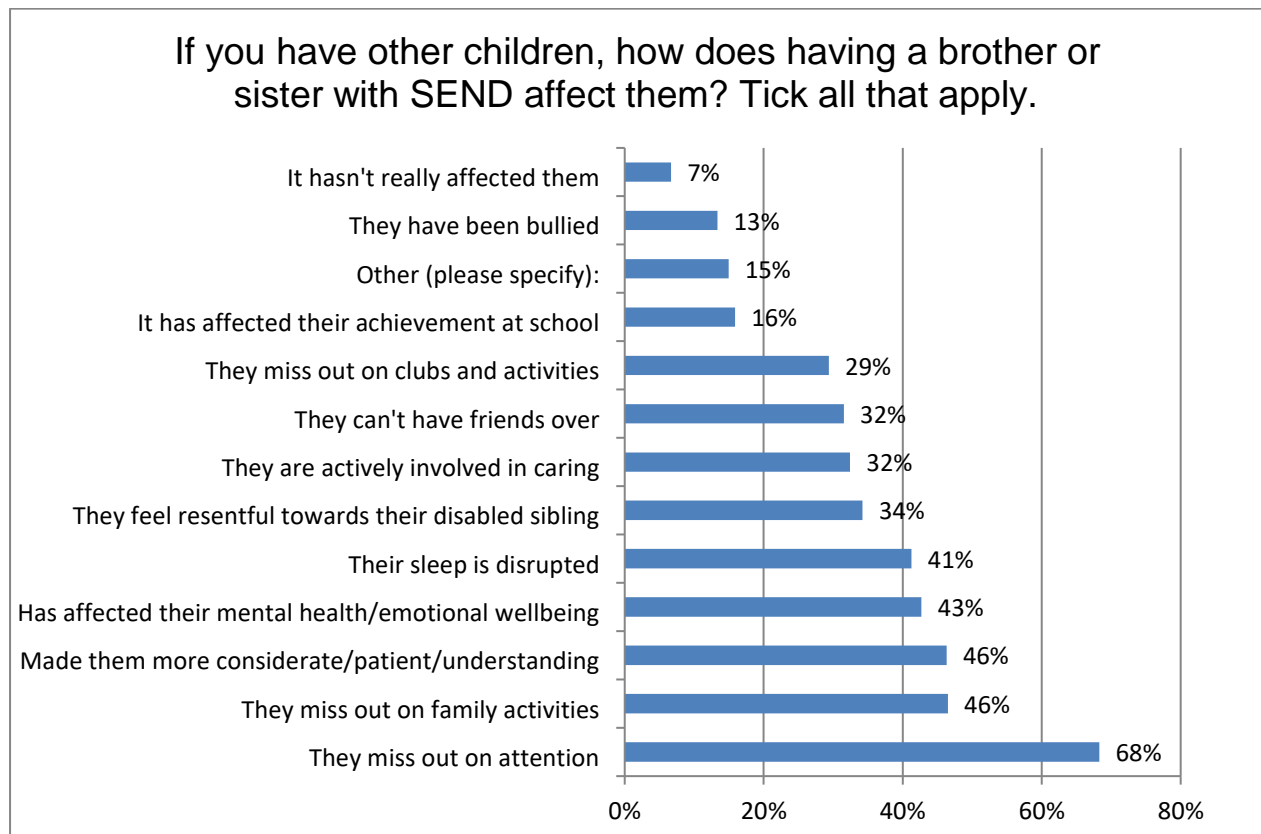
5.4 Impact on siblings (555 responses)

83% of respondents felt that having a disabled sibling had a negative impact on their other children.

A lack of parental attention was identified as the biggest issue (**68%**), followed by missing out on family activities (**46%**), a negative impact on sibling mental health and/or emotional wellbeing (**43%**) and disrupted sleep (**41%**).

Siblings of disabled children are at an increased risk of isolation, as they may not be able to have friends over (**32%**) or miss out on out-of-school activities (**29%**). **34%** of parents said that siblings felt resentful towards their disabled child.

Almost half of respondents (**46%**) also identified a positive effect, stating that it had made their other children more considerate, patient or understanding.



Most of the respondents who selected “Other” repeated answer choices given in the questionnaire, with some providing additional information, e.g.:

“Over 90% of our parental attention is given to our son with SEN. Over 90% of any disposable income is also spent on him. This means that opportunities that his siblings earn for themselves can't be taken up.”

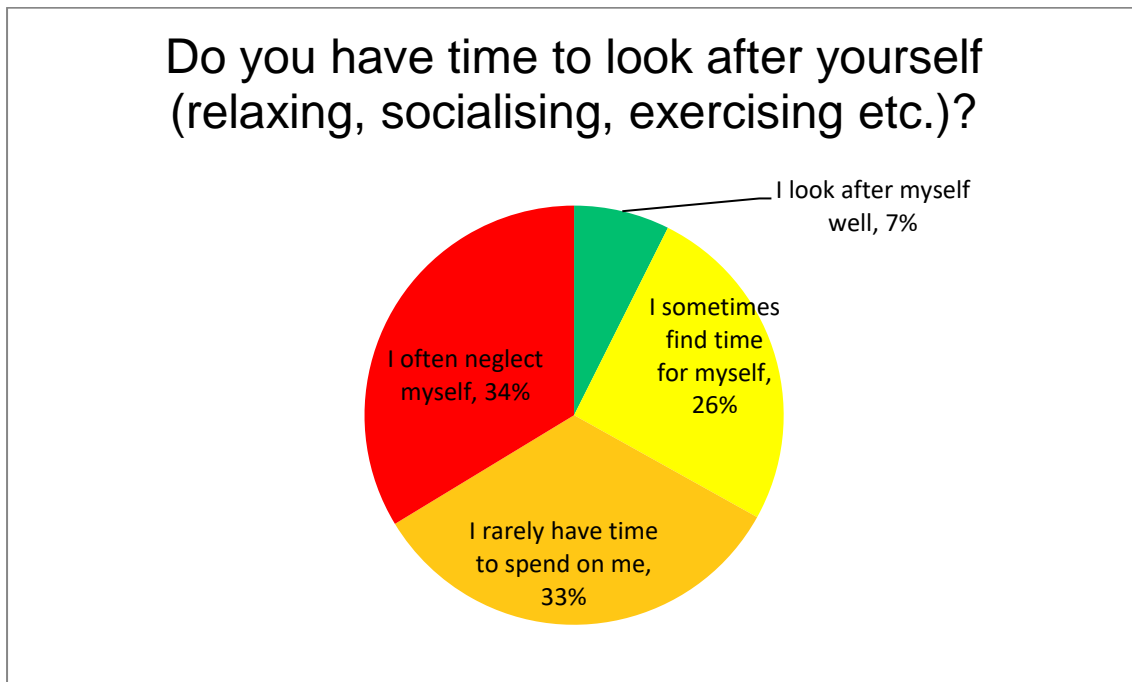
“They have to limit what they can do due to their sibling's sensitivity to noise which makes them annoyed. They also get hurt by them.”

“Stress levels are very high for parents and siblings as well as our son with a disability. [...] I had to give up work as our teenage daughter started self-harming due to the high stress levels in the family.”

Several respondents pointed out that all of their children had SEND, that their child with SEND was an only child, or that the only sibling was a baby. A few parents were concerned that siblings were copying problem behaviours from the child with SEND, and some worried that siblings may become carers in the future.

5.5 Impact on parents: looking after themselves (677 responses)

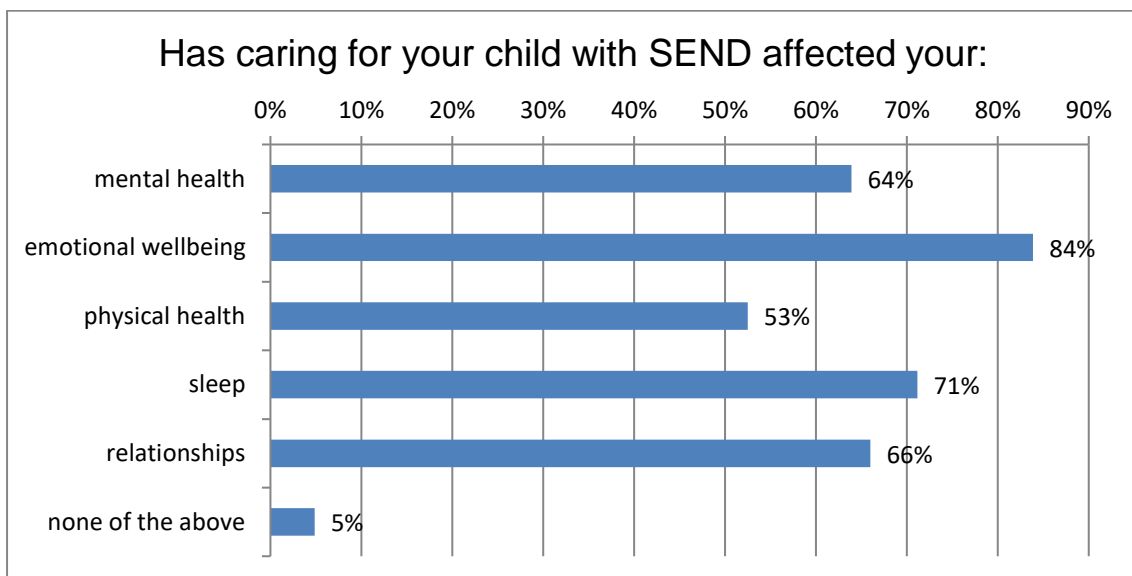
Over a third of parents (**34%**) said that they often neglected themselves. This is higher than in our 2014 survey, where **26%** of respondents said that they often neglected themselves.



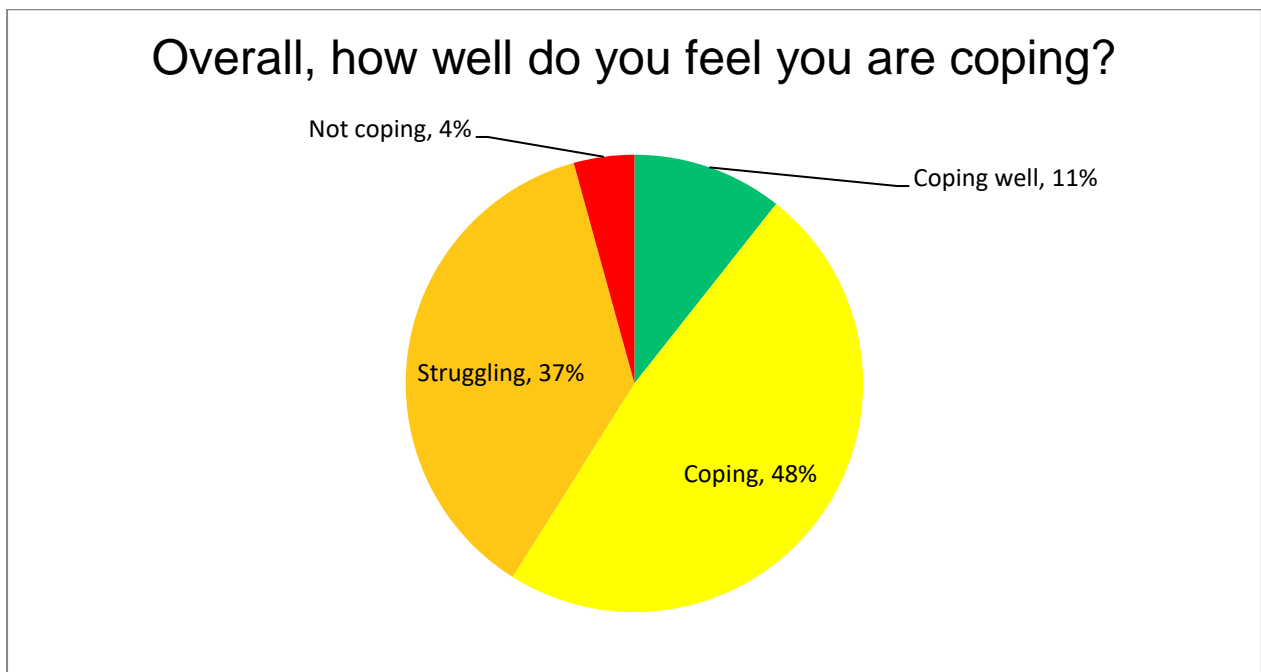
5.6 Impact on parents' wellbeing (676 responses)

95% of respondents reported that caring had affected their wellbeing, particularly their emotional wellbeing, their sleep and their relationships.

Compared to our 2014 survey, the percentage of parents who said that caring had affected their emotional wellbeing had increased from **78%** to **84%**, and the percentage of those whose mental health had been affected had increased from **49%** to **64%**. There was little change in the other areas.



5.7 Coping (677 responses)



41% of respondents were either “Struggling” or “Not coping”. This is more than in 2014 (**35%**).

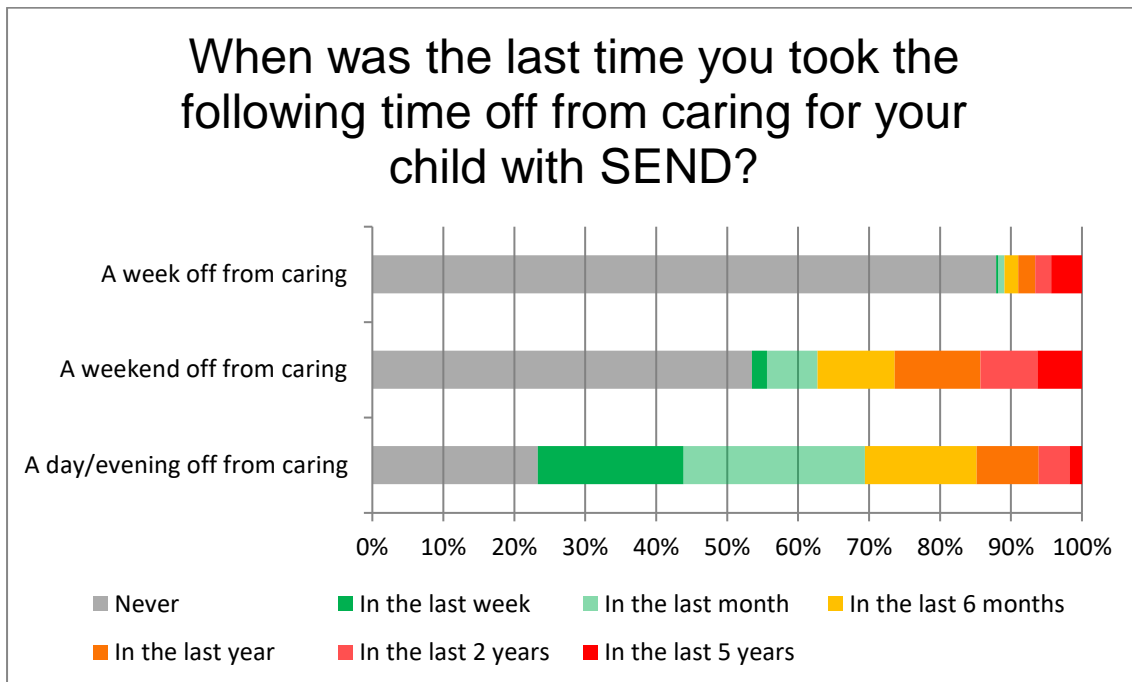
This group differed from the overall sample in that it included more parents with a disability or long-term illness, as well as more families with more than one disabled child, and more parents who also provided care for an adult. **65%** said that their child had Autistic Spectrum Disorder as their main impairment, compared to **56%** in the total sample. Problems with social interaction, sensory processing, challenging behaviour and sleep were more common than in the total sample.

Consequently, this group found it much harder to do everyday things and reported higher levels of isolation. The impact on siblings and parents was more pronounced. For example, **84%** of parents in this sample reported that caring had affected their mental health, compared to **64%** overall.

57% of those who said that they were “struggling” or “not coping” were not receiving any support from social care services. **66%** of those who did access support from social care services felt that it was insufficient to meet their needs. (By comparison, **55%** of the total sample said that their social care package was insufficient.)

5.9 Time off from caring (676 responses)

We asked parents when they had last had a break from caring for their child with SEND – a day, and evening, a weekend or a week off:



While it may be rare for parents of dependent children to have a week away from their caring responsibilities, having the occasional day/evening or weekend off is not unusual for most parents.

However, **23%** of the parents in our sample had never had a day or an evening off from caring, and **54%** had never had a weekend off from caring. The percentage of one-parent families and parents from BME backgrounds in this cohort was higher in the total sample.

5.9 Parents' training needs (596 responses)

We asked parents whether there was any training that would help them cope with the demands of caring for their child with SEND. **85%** of all survey respondents indicated a training need.

Parents' training needs



Most of the respondents who selected “Other” repeated answer choices given in the questionnaire, with some requesting more specific training, e.g. “Applying for an EHCP”, “Makaton/PECS” or “CBT for children and young people”. Where parents indicated additional training needs, these fell under the following headings:

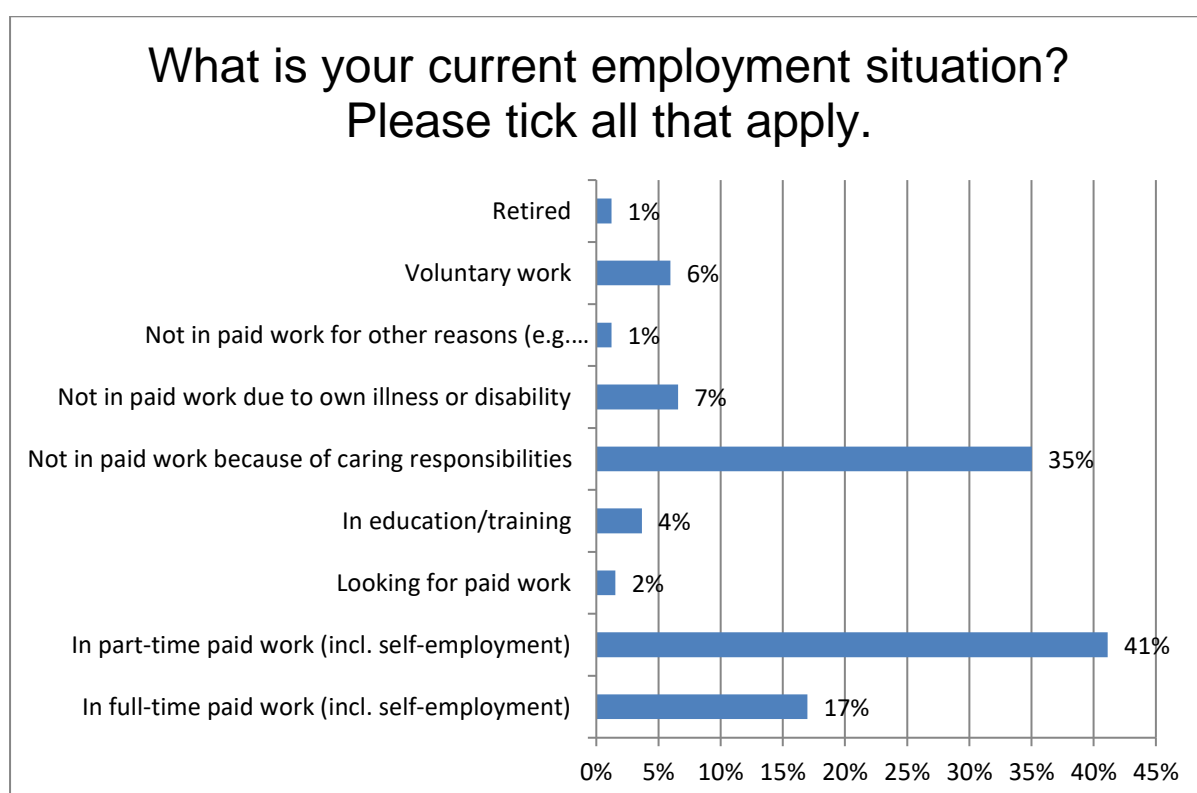
- Demand avoidance / PDA
- How to support siblings
- Teaching life skills / preparing for adulthood
- Support in school
- Travel / days out
- Working with professionals

5. Work and finances

6.1 Employment situation (654 responses)

Caring for a child with SEND can have a detrimental impact on parents' ability to work. Only **17%** of parents in our sample were managing to work full time, and **41%** were working part-time. However, this is more than in 2014 (**10%** and **38%** respectively). Overall, more parents were in paid work than in our 2014 survey (**58%** in 2019 compared to **48%** in 2014). It is possible that benefit cuts are forcing more parents to work.

There was a significant gender gap: **79%** of fathers but only **56%** of mothers in the survey were in paid work.



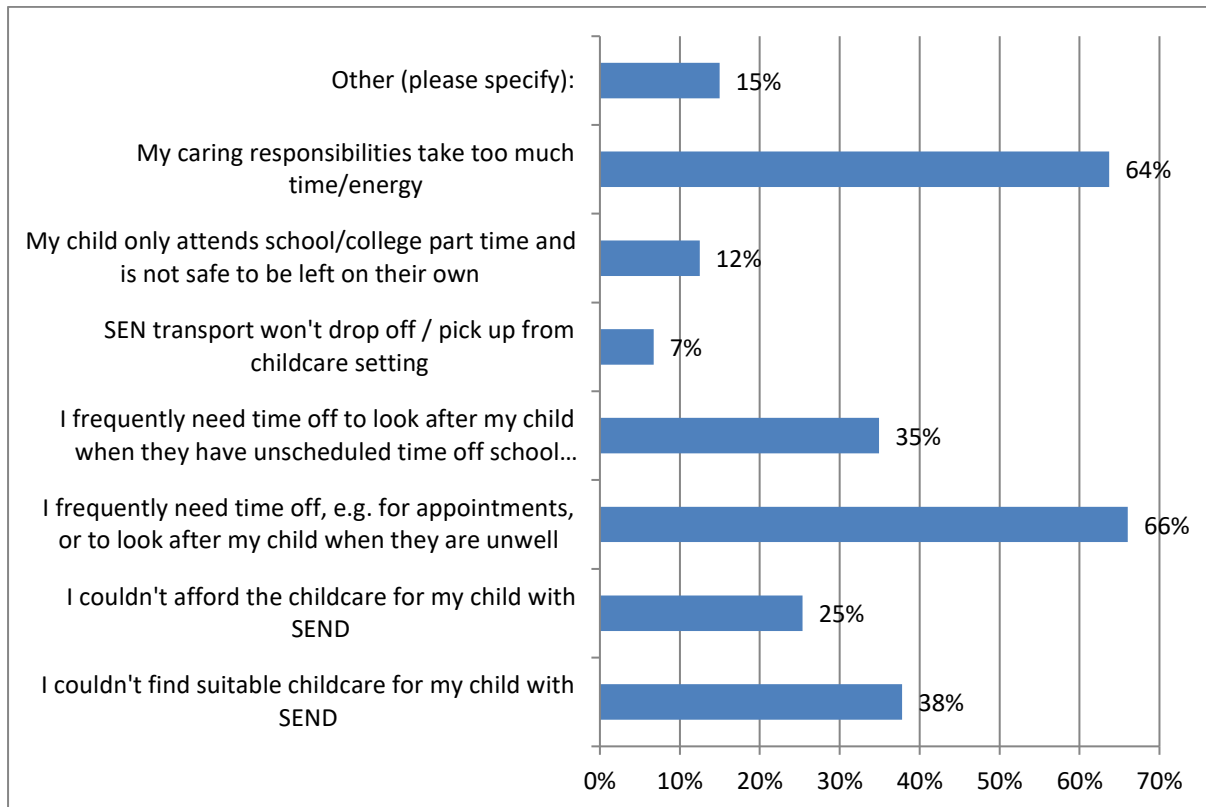
5.2 Impact of caring on parents' ability to work (629 responses)

Only a minority (**17%**) of respondents said that caring had not affected their ability to work. **37%** had given up work to cope with their caring responsibilities, **36%** had reduced their hours and **26%** had taken a less challenging job in order to care for their disabled child/children.

Parents who give up work can become very isolated, as they miss out on social contacts with co-workers and have less money to participate in leisure activities.

5.3 Factors determining parents' ability to work (521 responses)

We asked parents who felt that caring had affected their ability to work to tell us why. The biggest factors were having to take frequent time off due to their child's medical needs (65%), and a lack of time/energy (64%).



Responses highlighted that **issues with a child's education** can have a major impact on their parents' ability to work. **35%** said their child often had unscheduled time off school (e.g. due to exclusions), **12%** said their child only attended school or college on a part-time basis, and **7%** said that SEN Transport would not drop off or pick up from a childcare setting.

Another important factor is childcare: **38%** of parents said that they couldn't find suitable childcare, and **25%** said they couldn't afford the childcare for their child with SEND. Parents of non-disabled children often accept that they may need to work for little financial gain during the toddler years in order to improve their long-term career prospects. For parents of disabled children, however, the situation does not tend to improve over time, as their children may still need childcare right through secondary school. Childcare for disabled teenagers is scarce and can be expensive, making work an uneconomical option for many parents.

Most of the respondents who ticked "Other" provided more information about the existing answer choices, for example:

"I tried flexible working initially but the requirements in caring for my child (including administration, meetings, assessments) meant I could not continue working. Not enough hours in the day. Extremely stressful, had little support and isolated in this position. The initial process also coincided with caring for my elderly parent with dementia and cancer. It was an extremely difficult time all round. My priority had to be caring for my loved ones, whilst attempting to work. It was an impossible position and it impacted on my own health and well-being."

“He is barely at school. Within an hour on Monday I was rung to collect my son, and now he is excluded til Friday. It is impossible to keep any job as school cannot provide what he needs so exclude him constantly.”

Additional reasons given for not being able to work fell into the following categories:

- Parent’s own ill health
- Not being able to find a job that offers sufficient flexibility
- Caring for elderly parents as well as the child with SEND
- Home educating the child with SEND due to lack of a suitable school place
- Child not eligible for or able to access SEN transport

5.4 Impact of caring on family finances (643 responses)

We asked respondents to whether their family’s financial situation had changed as a result of caring for their child with SEND.

5% said they were better off, **58%** were worse off, and **37%** had seen no change.

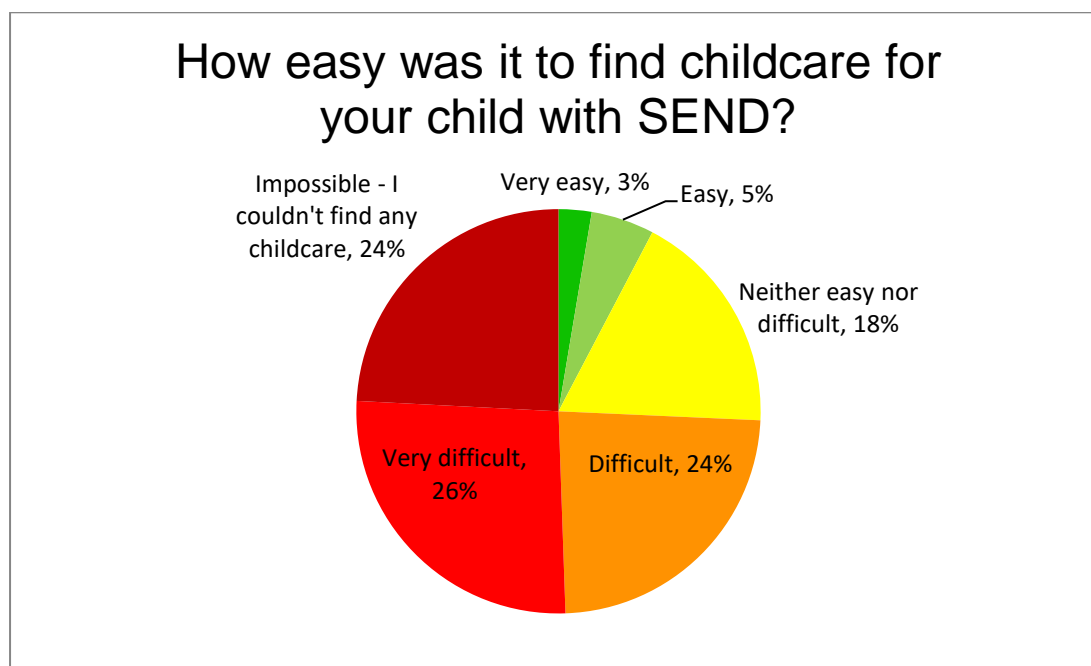
5.5 Families in receipt of means-tested benefits (647 responses)

45% of respondents were in receipt of means-tested benefits. This is less than in 2014, when this figure stood at **57%**. This could be a consequence of cuts and restrictions to benefit entitlements, parents increasing their earnings and/or work hours, or both.

6. Childcare

6.2 Finding childcare (455 responses)

We asked parents to tell us how easy it was to find childcare for their child with SEND. **Three quarters** of respondents said that it was “difficult”, “very difficult” or “impossible” to find childcare:



The picture was slightly more positive for parents of children aged 0-4 years. However, **60%** of the respondents in this group also said that finding childcare was “difficult”, “very difficult” or “impossible”.

6.3 Childcare arrangements (269 responses)

We asked parents to tell us what sort of childcare they used for their child with SEND:

Childcare provider	Percentage
Family member, friend or neighbour	48%
Personal assistant	21%
Mainstream after-school club	13%
Childminder	12%
Specialist holiday club	12%
Mainstream holiday club	9%
Private nursery	8%
Specialist after-school club	3%
Children's Centre	1%

Although family members, friends and neighbours still topped the list, there was less reliance on this kind of informal childcare than in our 2014 survey.

7. Education

7.1 Type of setting attended (621 responses)

A majority of respondents said that their child attended a mainstream setting:

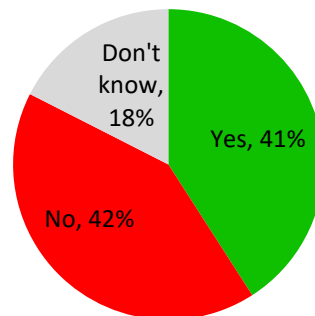
Answer choices	Responses
Mainstream school	46%
Special school	21%
Integrated Resource	8%
Sheffield College	6%
Nursery/children's centre	4%
Independent specialist provider	4%
Home educated as no other option	3%
Sheaf Training	1%
University	1%
Home and Hospital Service	1%
Home educated by choice	1%
Sheffield Inclusion Centre (PRU)	0%
None of the above	5%

17 respondents said they were home educating because of a lack of other options. **76%** of these parents said that home education was not adequate for meeting their child's needs.

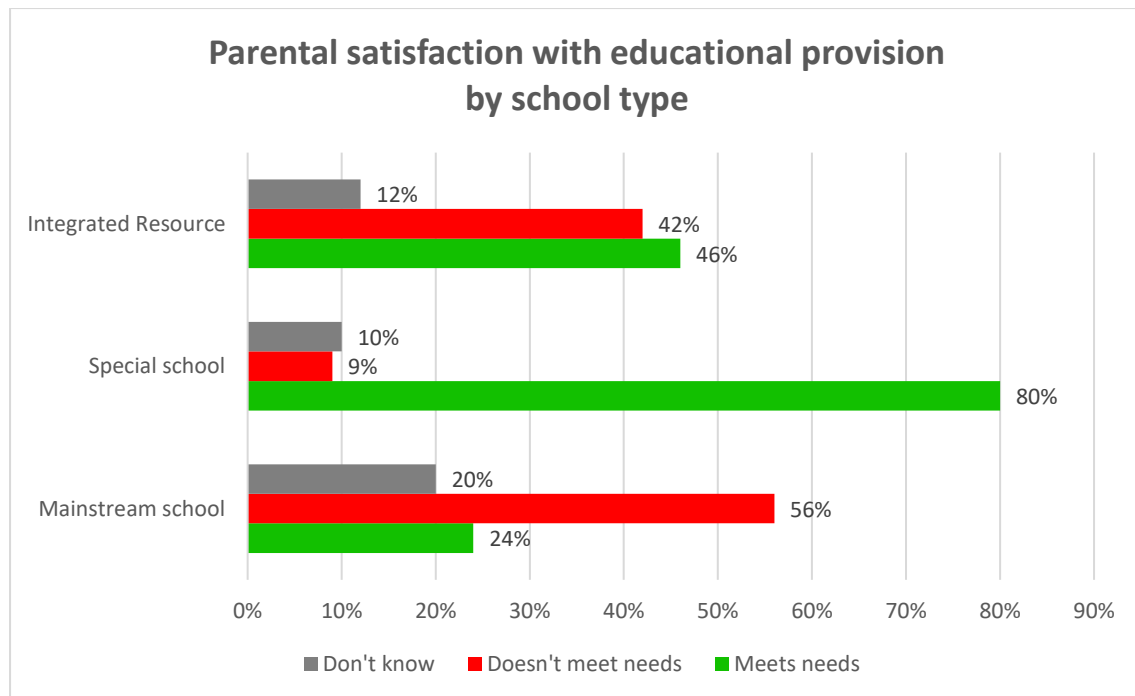
Of those who responded "None of the above", **69%** had a child in the 16-25 age range, and **10%** had a child aged 0-4 years.

7.2 Adequacy of provision (611 responses)

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



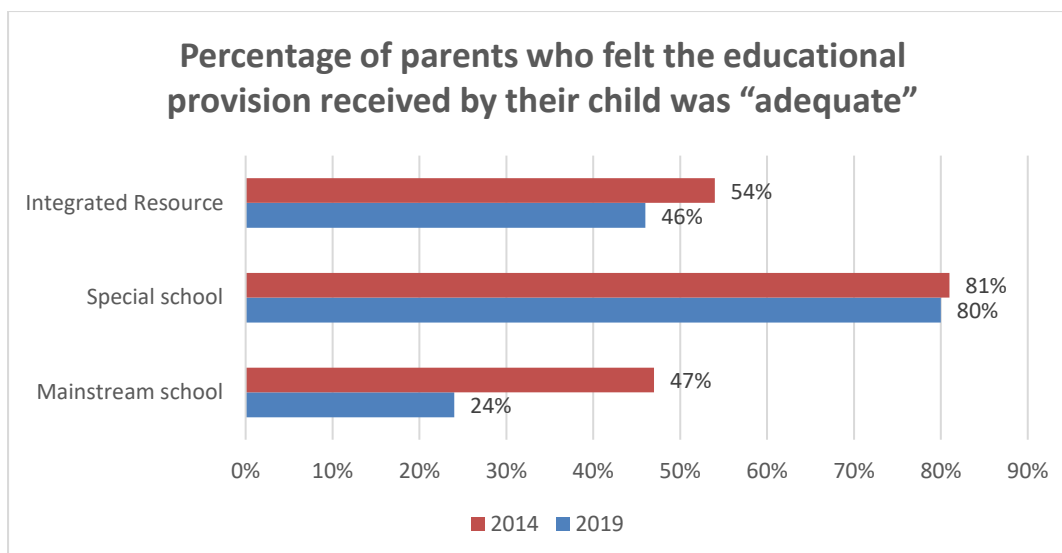
Satisfaction with educational provision varied significantly between school types:



Compared to our 2014 survey, there was a significant decline in satisfaction with mainstream schools. In 2014, **47%** of mainstream parents stated that the school was meeting their child's needs – in 2019, this figure had halved to just **24%**.

Satisfaction with **Integrated Resources (IRs)** had also reduced, and views about these units were mixed, with some parents stating that these units had become overcrowded and understaffed. It should be noted, however, that the number of IR parents in both samples was relatively small (50 respondents in 2019).

Satisfaction with **special schools**, on the other hand, remained high at **80%**. Many parents told us how much happier their child was since they had moved from a mainstream to a special school.



The concerns about mainstream education extended into the **post-16 sector**, with several parents highlighting concerns about insufficient support, staff expertise and communication at Sheffield College.

367 parents provided more information in the free-text box. The main reasons given for rating their child’s educational provision as “Not adequate” were:

- Poor or insufficient support
- Lack of understanding for child’s needs / lack of training
- Poor communication
- Child’s anxiety / mental health issues
- Child not coping with the school environment
- Lack of funding

Other issues – all mentioned by several respondents - included: child not in school, child making insufficient progress, EHCP not being followed, curriculum not challenging enough, no suitable provision available, on partial timetable, setting can’t meet needs, child has been excluded, child needs a specialist placement, no dyslexia support, child is socially isolated.

“Our school barely has enough funds to educate “normal” children, never mind those who need extra help.”

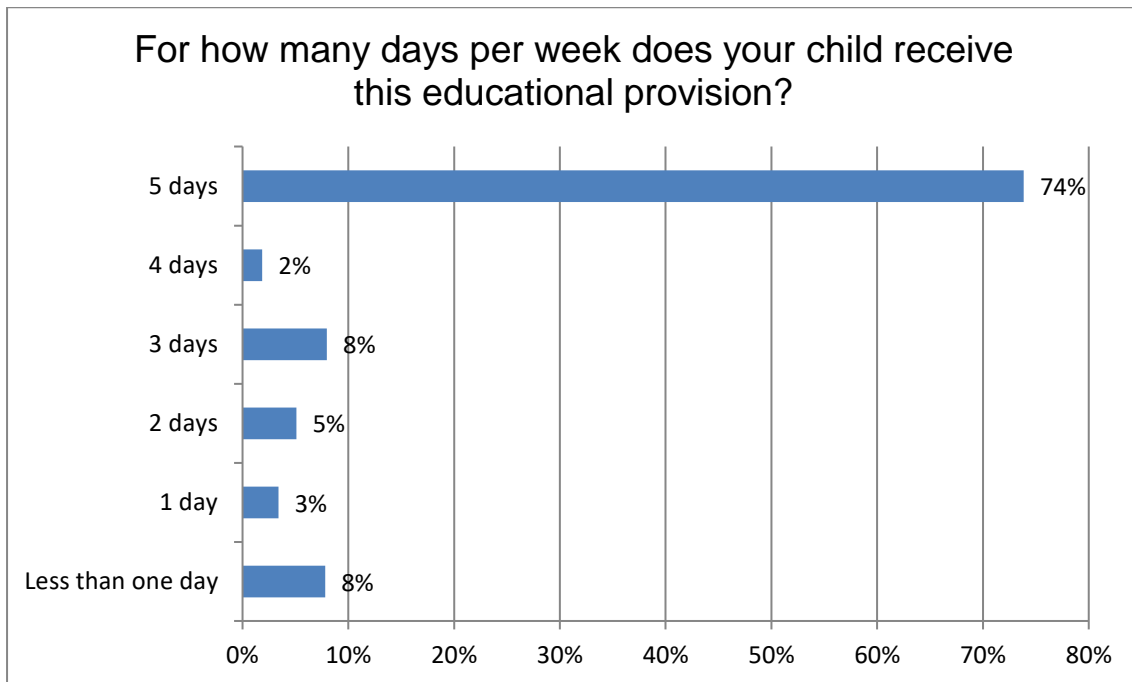
Funding is clearly important, but very often the element that makes or breaks a child’s experience in mainstream is the ethos of the school. Whilst some schools embrace diversity and manage to be inclusive on a shoestring budget, others appear to regard learners with SEND as little more than an inconvenience. We heard from several parents who felt that they had no other option but to home educate.

“My child was forced out of education eight months ago. School’s reasoning appears to be lack of resources, but there was a substantial lack of will. But no one in Sheffield SEND seems overly concerned. What are they doing?”

Several parents told us that their child was not a priority for support because they **masked their difficulties at school** – often at the expense of their mental health.

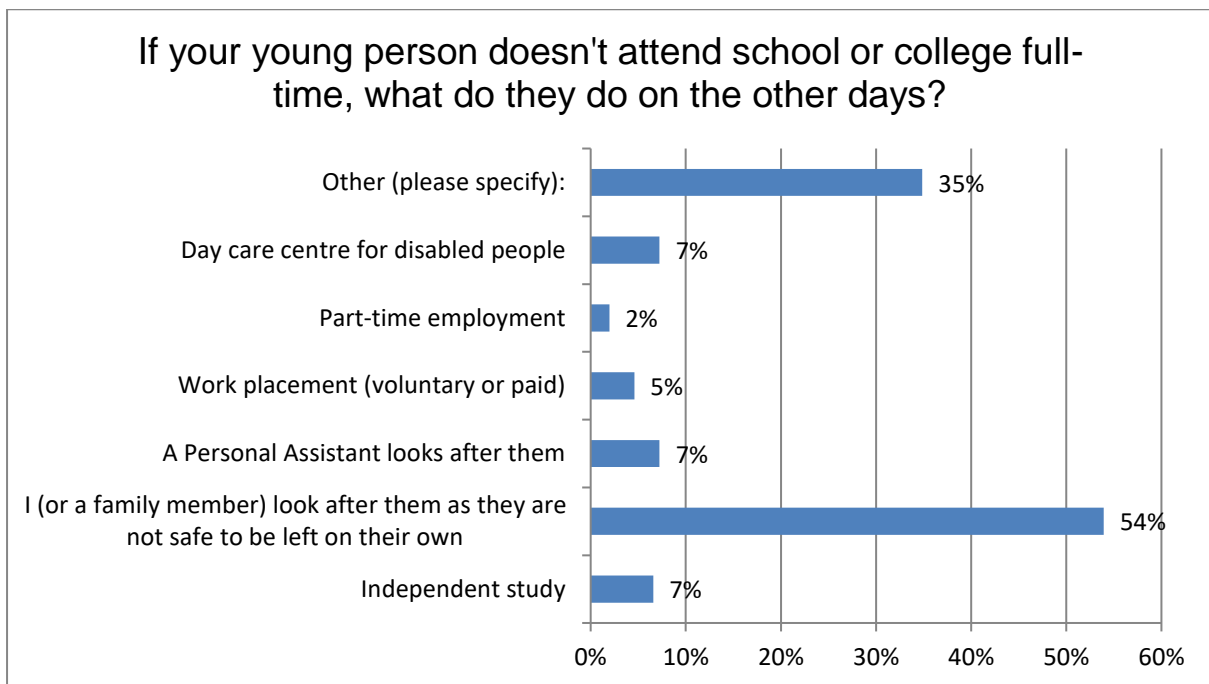
“Due to daughter having ASD she masks her condition at school resulting in meltdowns at home focusing on negative issues at school.”

7.3 Days of provision per week (589 responses)



It is unsurprising that many of the children who receive less than five days of educational provision per week are in the 0-4 and 16-25 age groups. However, we also found that **18%** of mainstream pupils aged 5-15 years did not attend school for five days per week. **51%** of these pupils had EHC plans.

7.4 Looking after learners who do not attend school or college full time (152 responses)

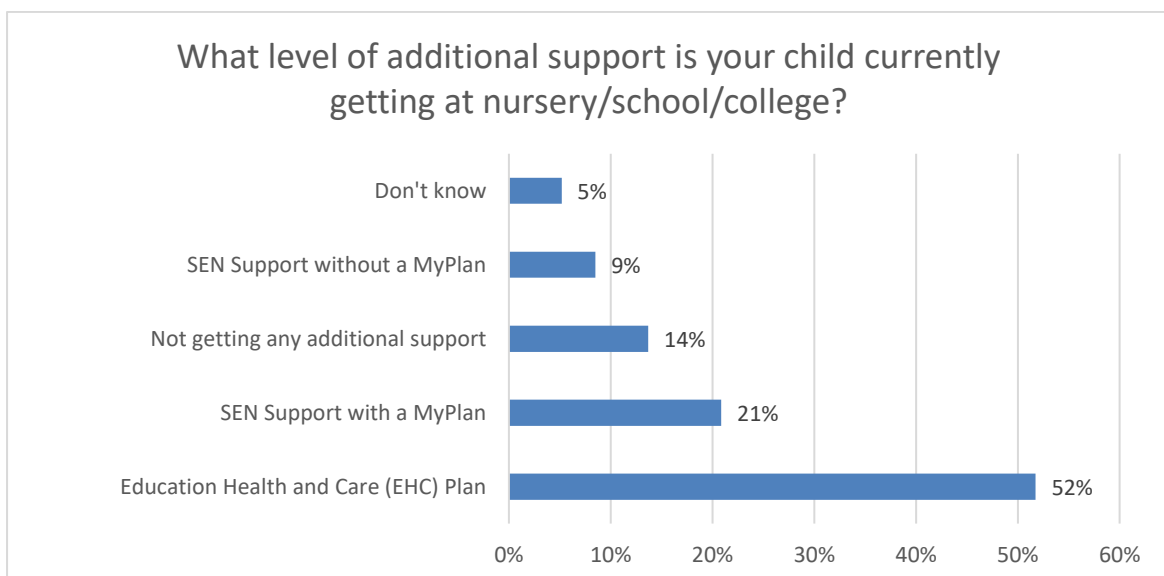


Having to look after a child or young person who doesn't attend school or college full-time can have a detrimental effect on their parents' ability to work; **50%** of these parents said they were not in paid work because of their caring responsibilities.

Most of the respondents who ticked "Other" repeated the existing answer choices or provided more detailed information about them. A small number of respondents mentioned other provisions, such as home education, volunteering, child unable to attend full time due to ill health, nurture groups, alternative provision, and the young person spending time on their own.

7.5 Level of additional support in education (599 responses)

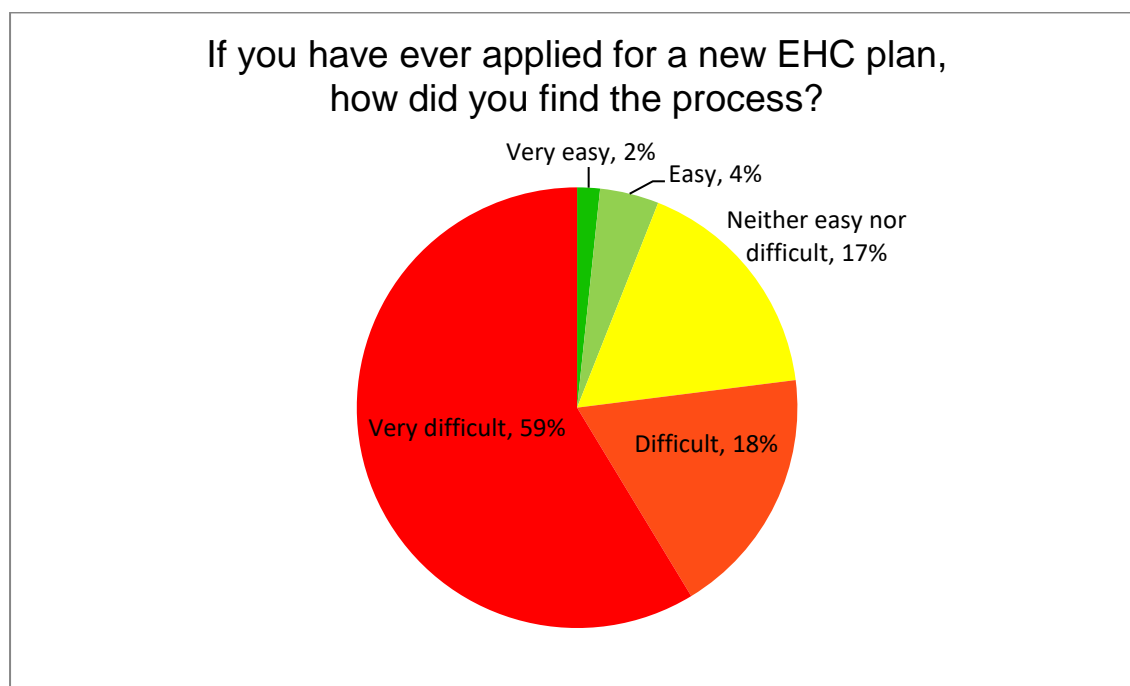
There was a fairly even split between parents of children with and without EHC plans:



7.7 Parental satisfaction with the EHC needs assessment process (300 responses)

We asked parents to tell us how they found the process of applying for a **new** EHC plan, and specifically instructed them not to answer the question in relation to transfers from a statement of SEN. However, the large number of responses suggests that some parents may have answered the question in relation to statement-to-EHCP transfers anyway.

77% found the process “difficult” or “very difficult”:



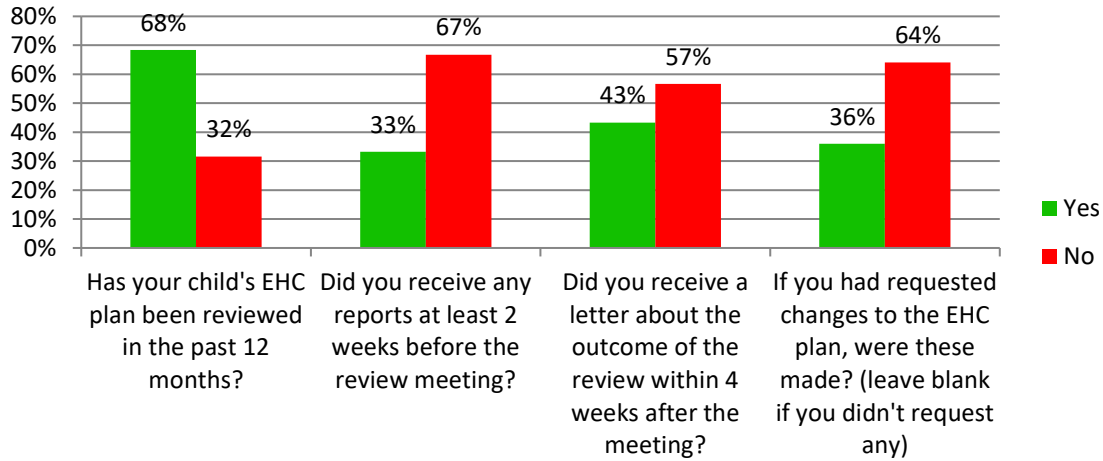
7.7 Parental experience of the annual review process (352 responses)

We asked parents to tell us about their experience of the annual review of their child’s EHC plan. Their responses show that both schools and the local authority are in frequent breach of SEND legislation:

- The local authority must review the EHC plan at least every 12 months, but **32%** said that their child’s plan had not been reviewed in the past 12 months.
- The school (or, if the child attends another institution, the local authority) must circulate advice and information at least two weeks before the review meeting, but **67%** said this had not happened.
- The local authority must notify the parents of the outcome of the review within four weeks of the meeting, but **57%** said they hadn’t received anything.

In addition, **64%** of respondents said that changes that they had requested to their child’s EHC plan had not been made. Whilst there is not legal duty on the local authority to make changes requested by parents, this percentage seems very high.

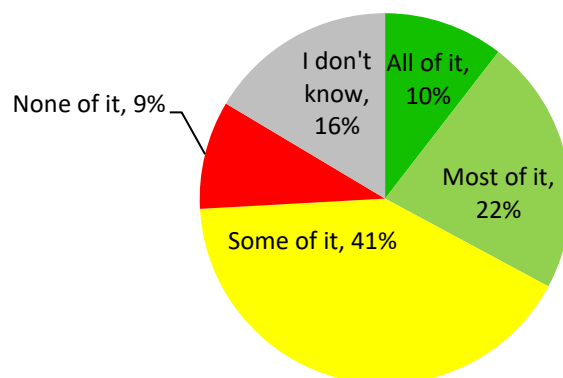
If your child has an EHC plan, please tell us about your experience of the annual review process.



7.7 Implementation of My Plans and EHC plans (487 responses)

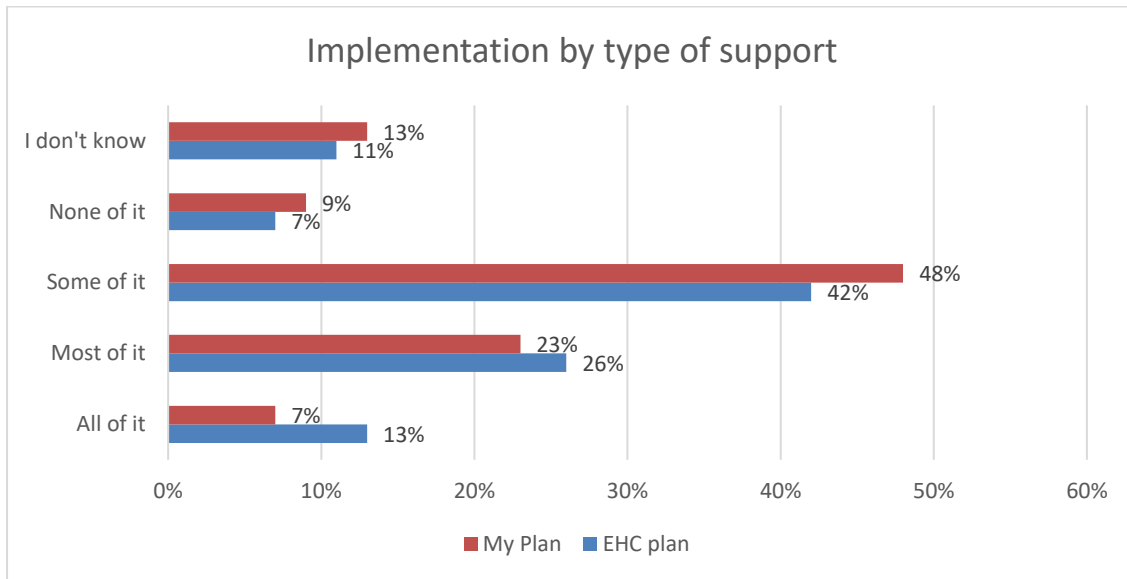
We asked parents of children with My Plans and EHC plans to tell us whether their child was getting the help and support described in their plan.

If your child has a MyPlan or an EHC plan, are they getting the help and support that is described in it?



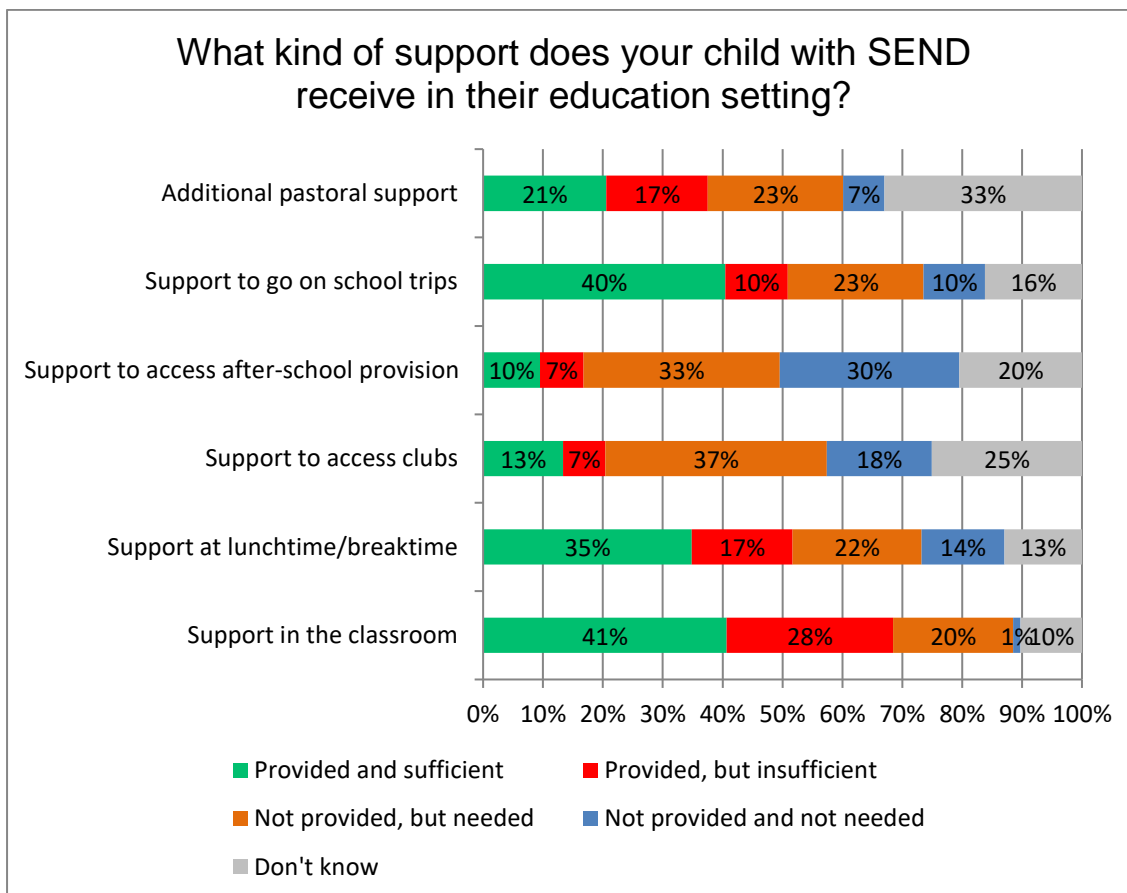
EHC plans are statutory, which means there is a legal duty on the local authority to arrange the special educational provision described in the plan, and on the Clinical Commission Group to make the health provision. My Plans, on the other hand, are non-statutory and so do not confer any legal rights.

We compared responses from parents of children with My Plans to those of children with EHC plans, but found little difference:

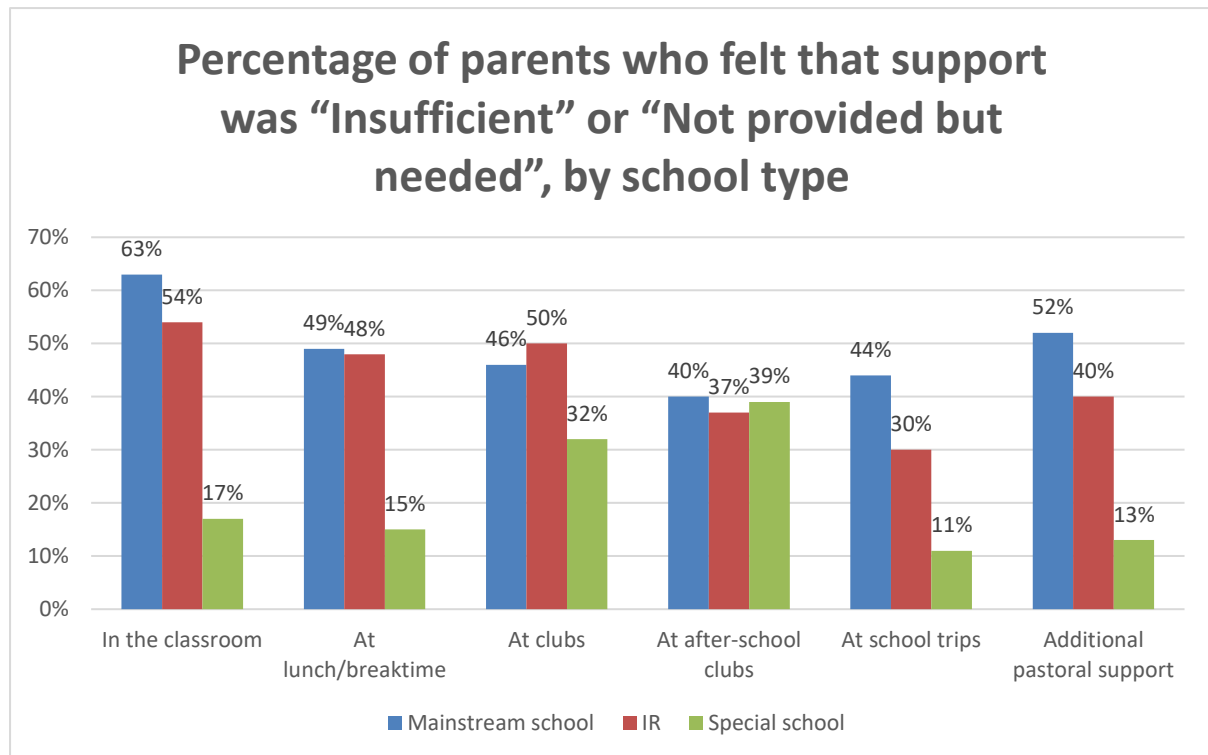


7.9 Support in education setting (588 responses)

We asked parents what kind of support their child received in their education setting, and whether this was sufficient to meet their needs:



Responses differed significantly between school types, with parents of children in mainstream schools and Integrated Resources (IRs) far more likely to say that support was “insufficient” or “not provided, but needed” than parents of children in special schools. The only exception was support to access after-school provision, where there was little difference between the three school types.

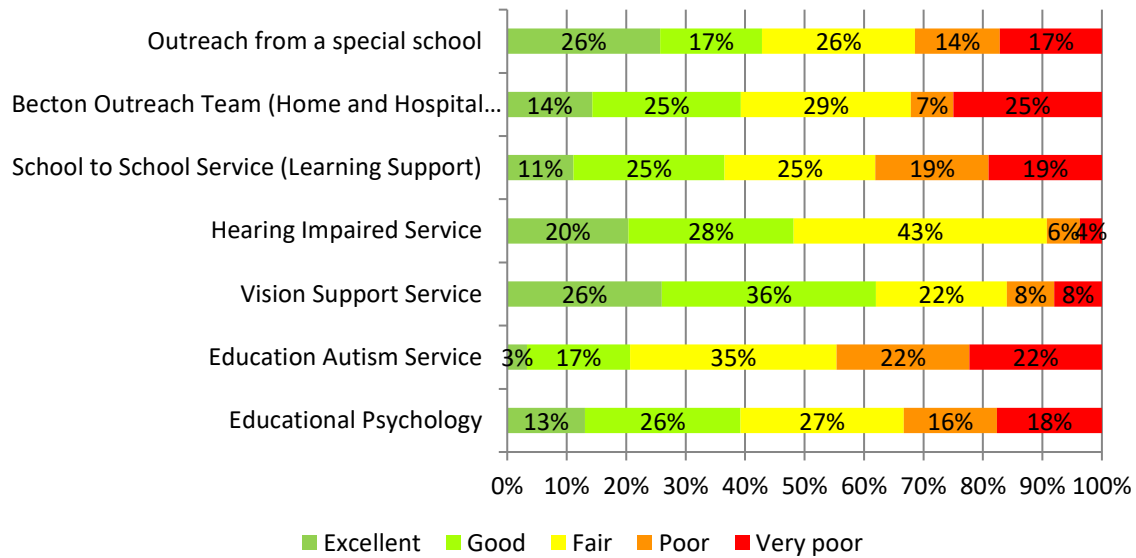


Compared to our 2014 survey, parental satisfaction with the support provided in mainstream schools and IRs had decreased significantly.

7.7 Quality and quantity of educational support services (252 responses)

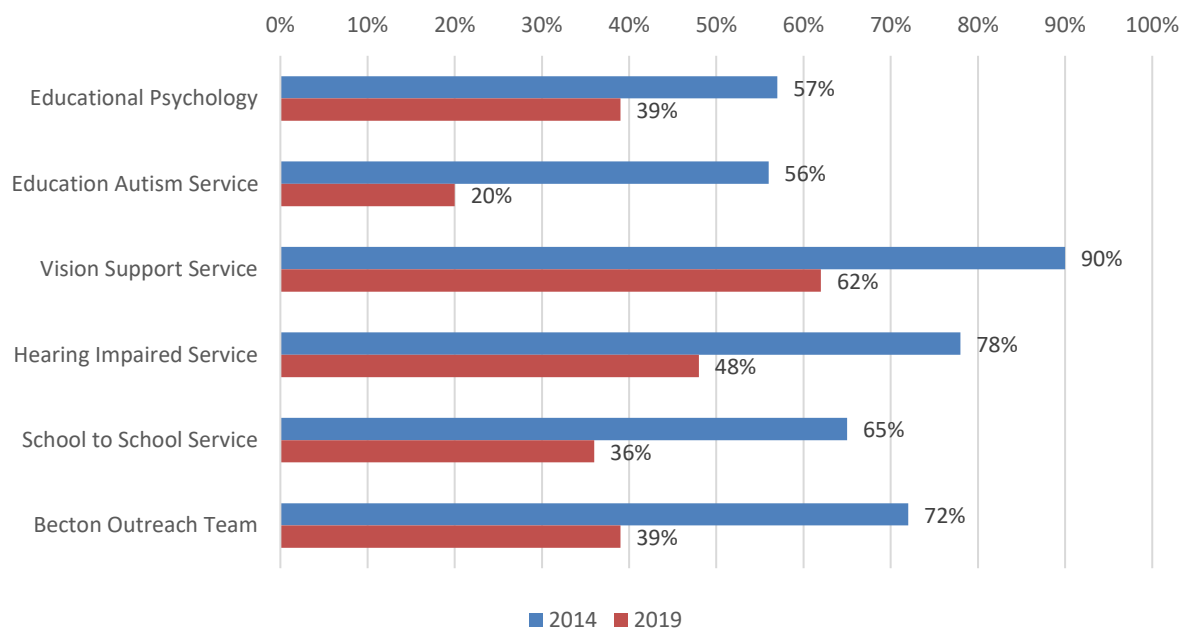
We asked parents to rate educational support services in terms of quality and quantity.

Quality of education support services

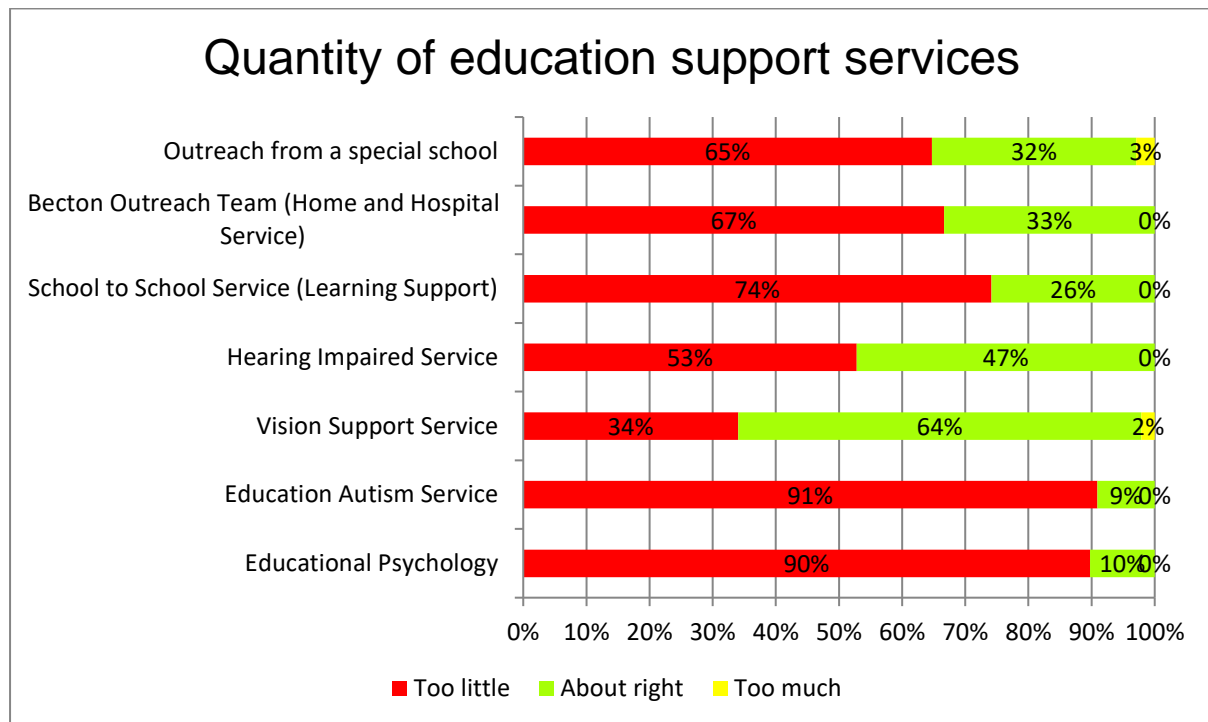


Quality ratings show a marked decline in parental satisfaction with education support services compared to 2014. This applies to **all** of the services listed (with the exception of special school outreach, which was not part of the formal offer at the time of our previous survey).

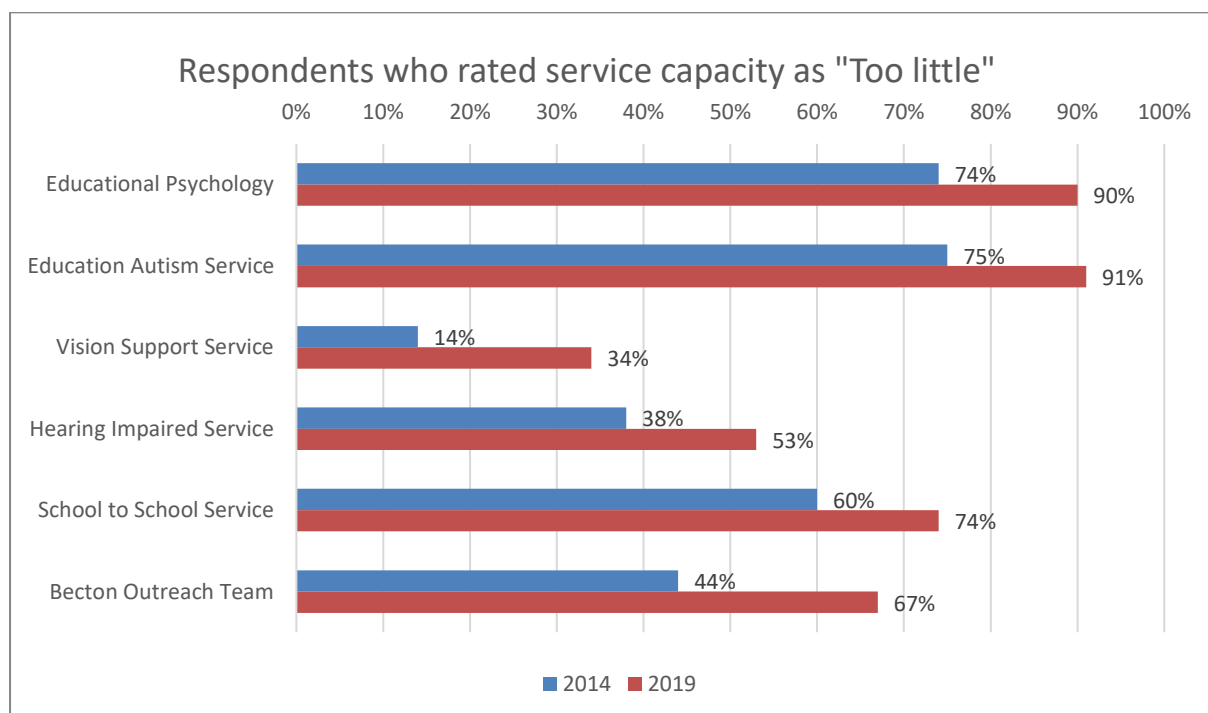
Respondents who rated services as "Good" or "Very good"



Quality ratings must be considered in the context of service capacity, which is a known issue for many services:



Again, there was a marked deterioration compared to 2014, for **all** of the services listed:



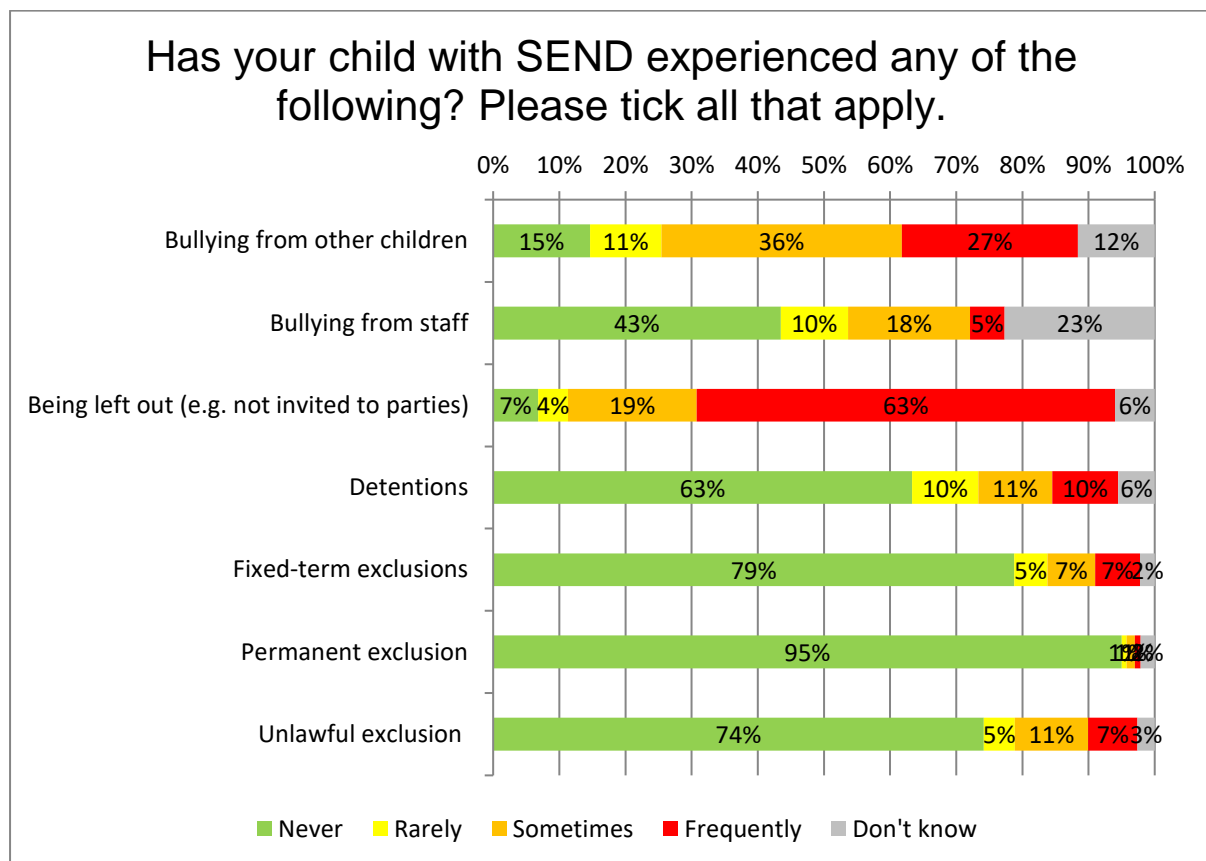
7.10 Bullying, social isolation and exclusions (606 responses)

Responses in this section show that bullying from other children affects a large percentage of children with SEND. **63%** of parents said that their child had “sometimes” or “frequently” been bullied by other children. This represents a **10%** increase against our 2014 survey.

63% of the children in our sample had “frequently” been left out (e.g. not invited to parties). This is a significant increase compared to 2014, when **33%** of respondents reported that their child had frequently experienced social exclusion.

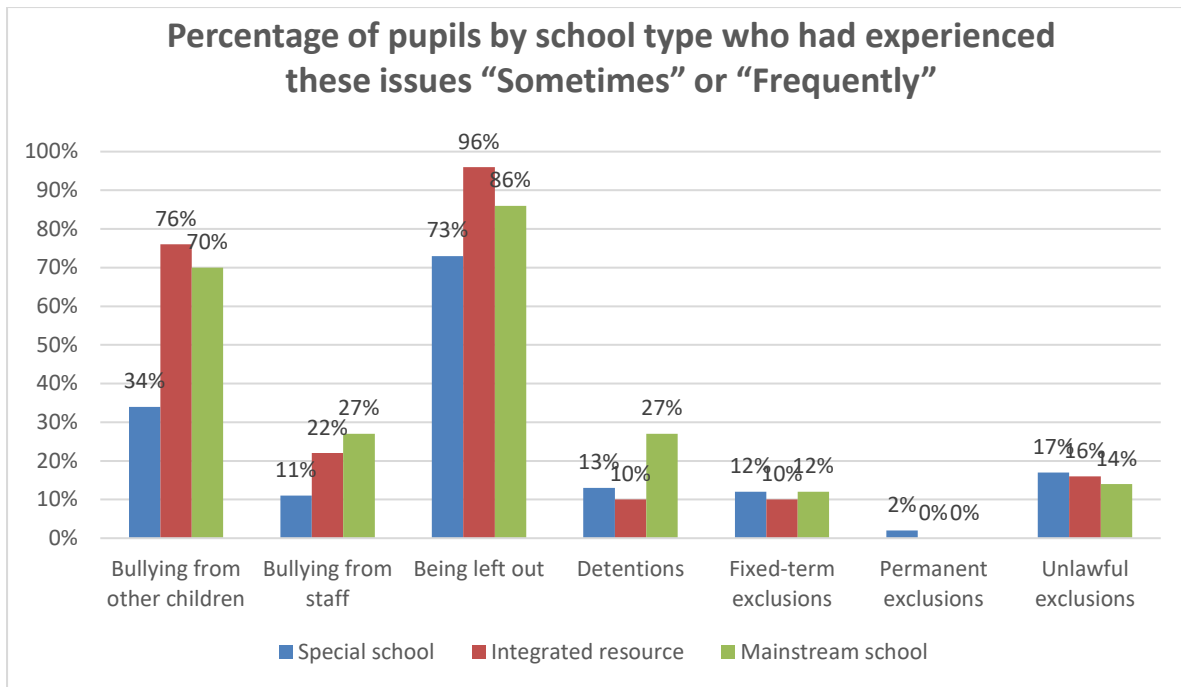
While it may seem unthinkable that these vulnerable children would also suffer bullying from staff, a total of 140 parents (**22%**) said their children had experienced this “sometimes” or “frequently”.

Rates of fixed-term exclusions and unlawful exclusions (e.g. child sent home or asked to stay at home because school did not have enough support staff) remained high. As we did not ask parents to limit their answers to a specific time period, a direct comparison with local and national exclusion statistics is not possible.

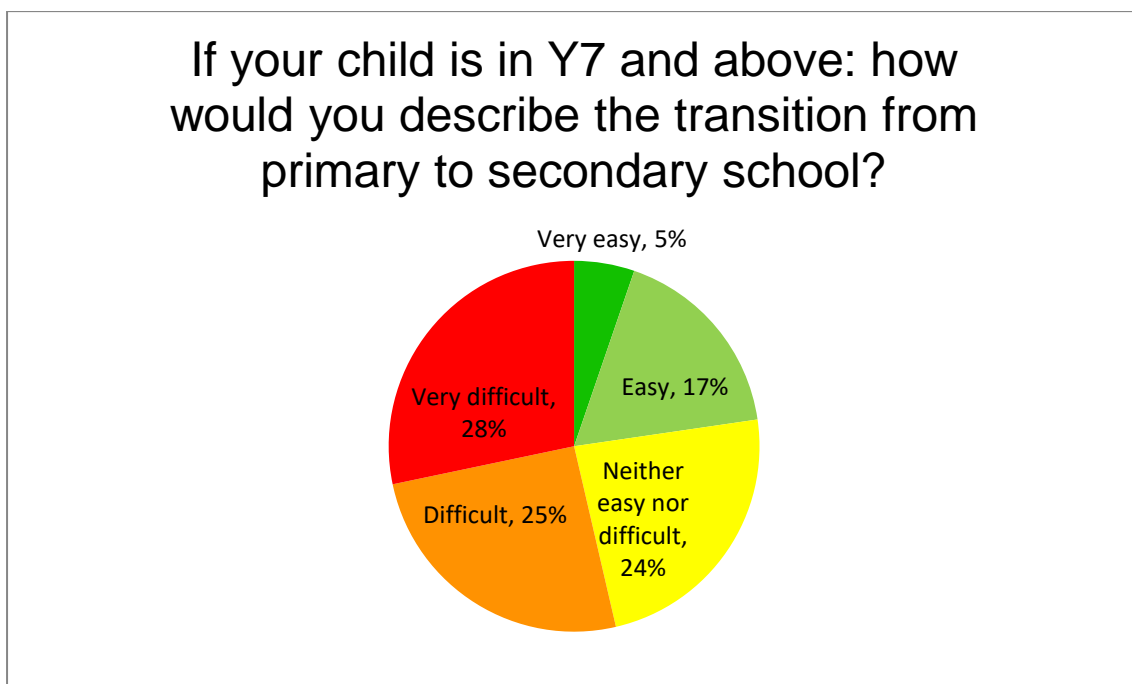


We analysed the responses by school type and found that bullying from other children and being left out were more frequent in IRs than in mainstream schools.

We also found that **17%** of special school pupils had experienced unlawful exclusions – a higher percentage than in mainstream schools and IRs.



7.11 Transition to secondary school (304 responses)



53% of respondents found the transition from primary to secondary school “difficult” or “very difficult”. However, many parents also provided examples of good transition support. These included:

- teachers carrying out home visits before children start in Reception;
- extra transition visits and summer school for children moving up to secondary school;
- secondary teachers visiting Y6 children in primary school;

- good information sharing between schools;
- assessment, training and support provided by specialists (e.g. speech and language therapists, epilepsy nurses) for primary and secondary school staff before the transition to secondary school.

“Transition to secondary school was very rocky, with a temporary exclusion and possible total exclusion for our very lovely, bright boy because of the school's misunderstanding of his condition. However, the intervention of the MAST team and school nurse has put us back on an even keel and we are told he is one of the best performing pupils all round so far in his second year.”

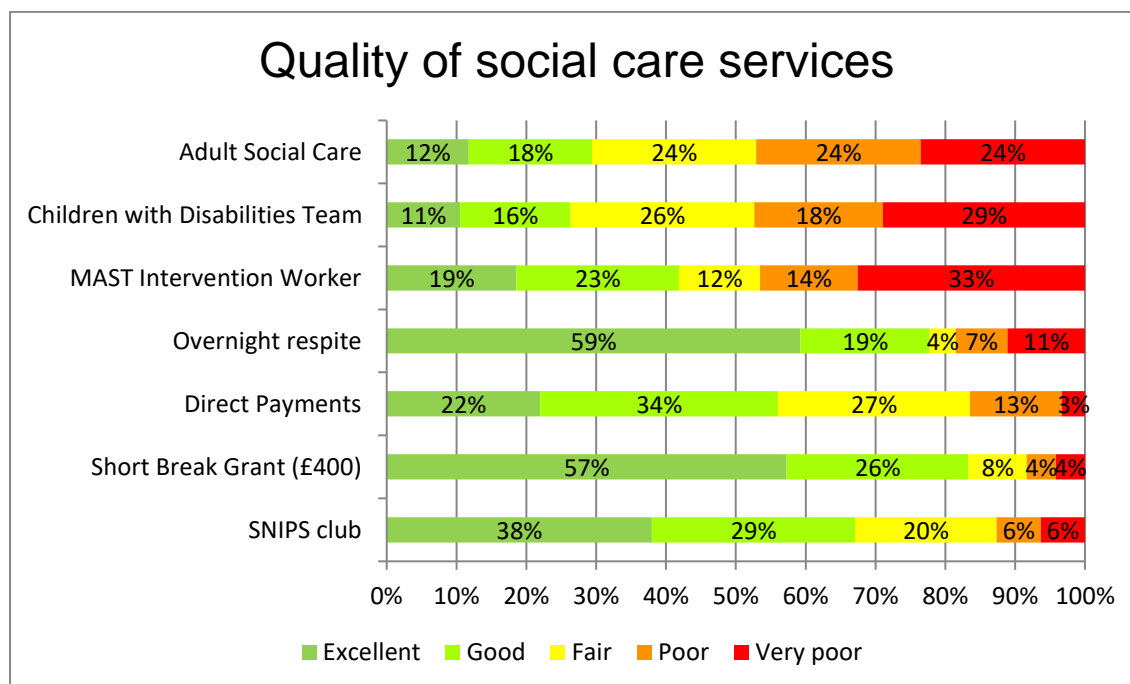
8. Social care

8.1 Families in receipt of a social care service (605 responses)

37% of respondents were receiving a social care service such as SNIPS, MAST, overnight respite, the short break grant or direct payments, 63% were not.

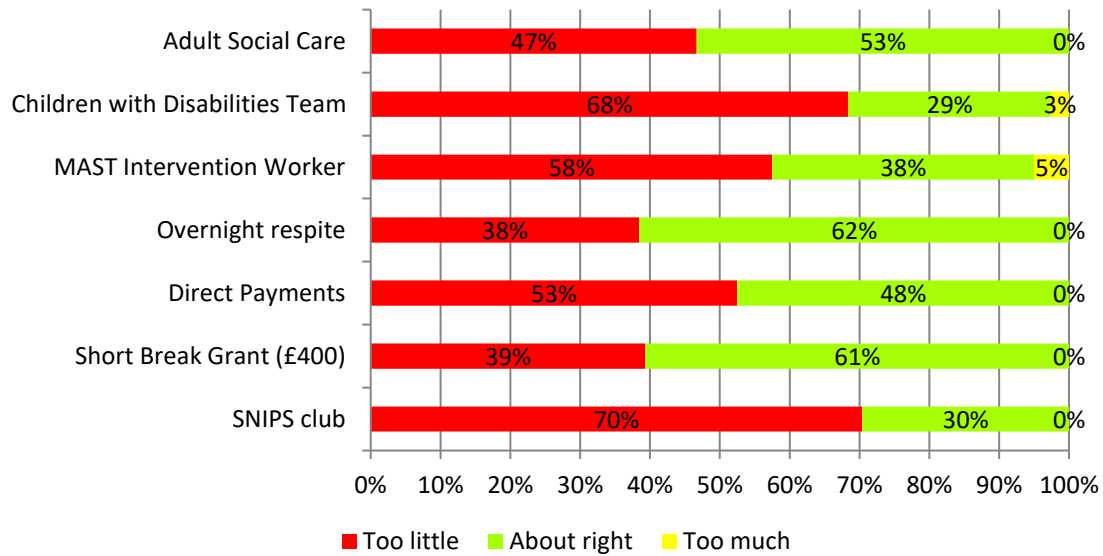
8.2 Quality and quantity of social care services (259 responses)

We asked parents to rate social care services in terms of quality and quantity. There was no equivalent question in our 2014 survey. Free-text responses to the 2014 survey, however, did indicate a high level of dissatisfaction with the children’s and adult social care teams. The current survey seems to bear this out, with almost half of all respondents rating adult social care, the Children with Disabilities Team and MAST intervention workers as “poor” or “very poor”.



Responses also highlight a lack of capacity, particularly in the Children with Disabilities Team and SNIPS. In relation to Direct Payments and the Short Break Grant, it is not clear whether “too little” means that respondents regarded the level of funding as too low or if they felt that the teams allocating the funding had too little capacity.

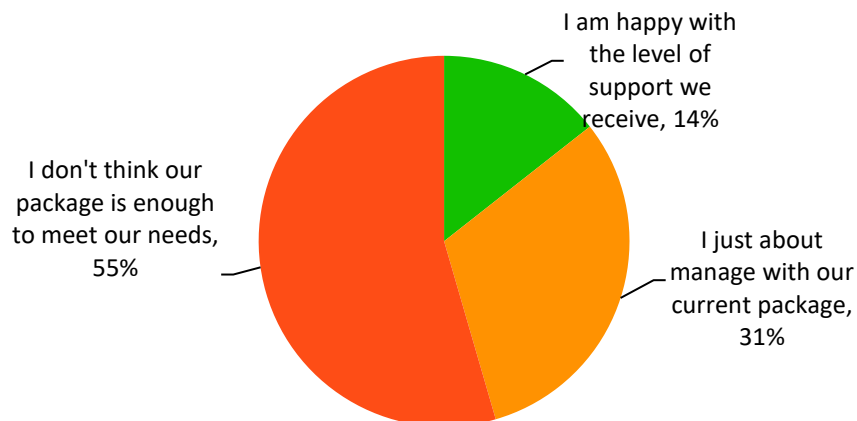
Quantity of social care services



8.4 Sufficiency of social care package (389 responses)

It should be noted that the total number of responses to this question (389) was significantly higher than the number of parents who had stated that their family was in receipt of a social care service (225). Free-text comments indicate that many respondents who ticked “I don’t think our package is enough to meet our needs” were not accessing any support from social care, but felt that they needed this.

Which of these statements best describes how you feel about the social care package your family receives?



The main reasons given by those who felt their care package was insufficient were:

- **Not accessing support from social care due to lack of information**

“We get no support and don't understand how to access a short break grant or SNIPS and don't know who to go to for help.”

- **Waiting for application to be approved**

“We have been waiting for MAST support for 8 months so far”

- **Support previously provided was removed**

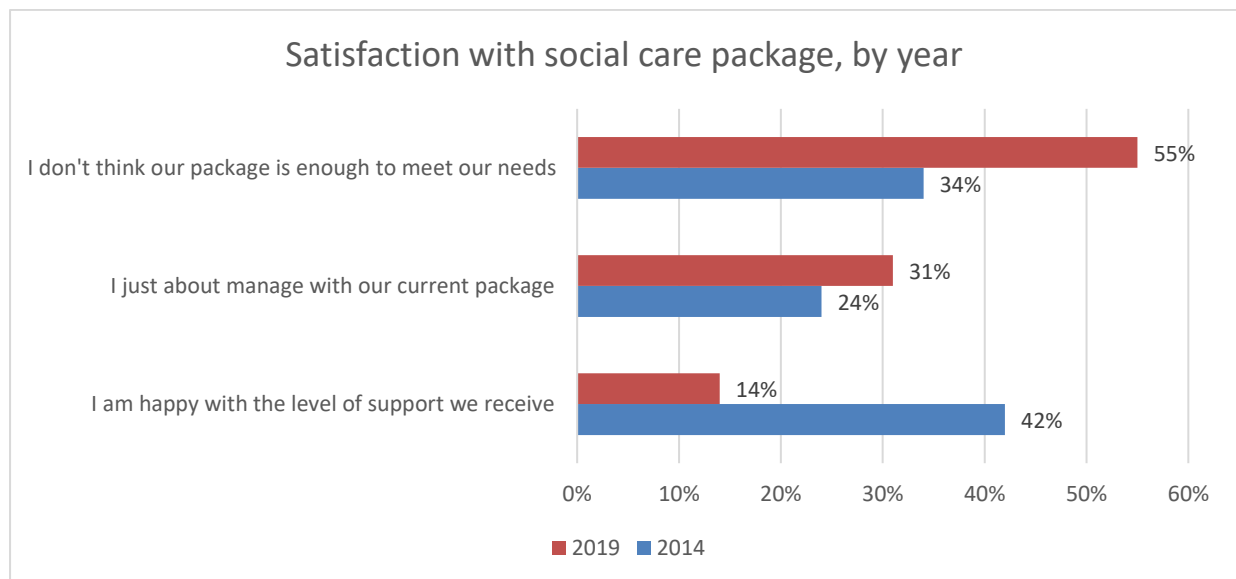
“We had all our child's social care package removed due to funding. My child is now isolated.”

- **Not eligible for support, or support offered not suitable**

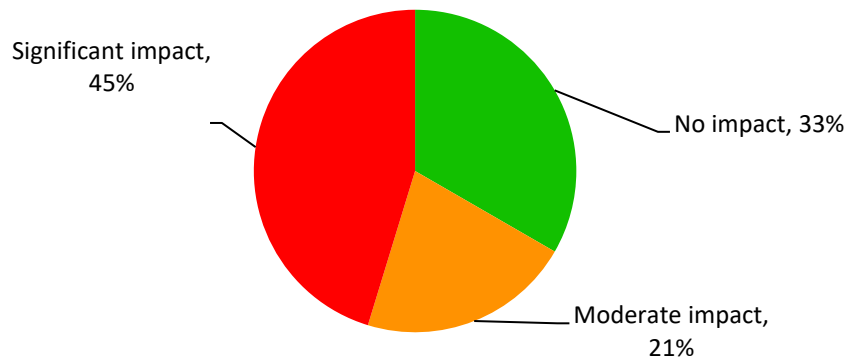
“You seem to have to be at breaking point to receive any services. This is not a good approach.”

“I don't seem to be entitled to anything, despite having 2 boys with ASD. Honestly I am at breaking point in most school holidays. (...) The SNIPS club we were offered and went to for a few weeks so terrible, totally unsuitable. On paper and form what they said it should have been perfect, but the 1:2 person to look after them wasn't ever there, the quiet room wasn't there, they didn't do any of the activities on the programme they gave me and it caused such huge anxieties in both my children they still years in won't go to any holiday club now.”

Compared to our 2014 survey, the percentage of those who felt their package was not enough to meet their needs had risen from 34% to 55%:

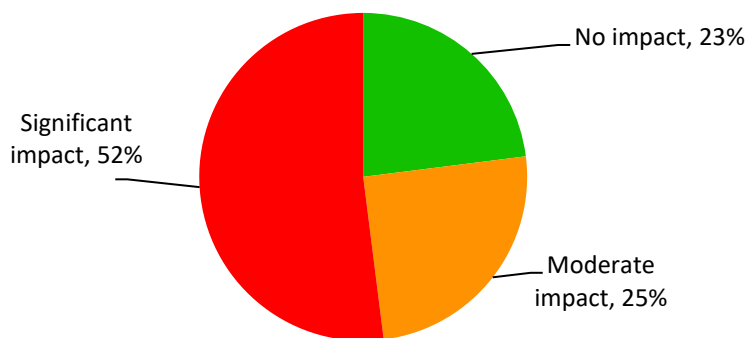


Sheffield City Council has decided to make changes to the Short Break Grant and SNIPS clubs. How do you think these will affect your family?



The total number of responses to this question (528) was much higher than the number of parents who had stated that they were in receipt of a social care service (225). If we only look at respondents who are **currently** in receipt of a social care service, the severity of the impact increases:

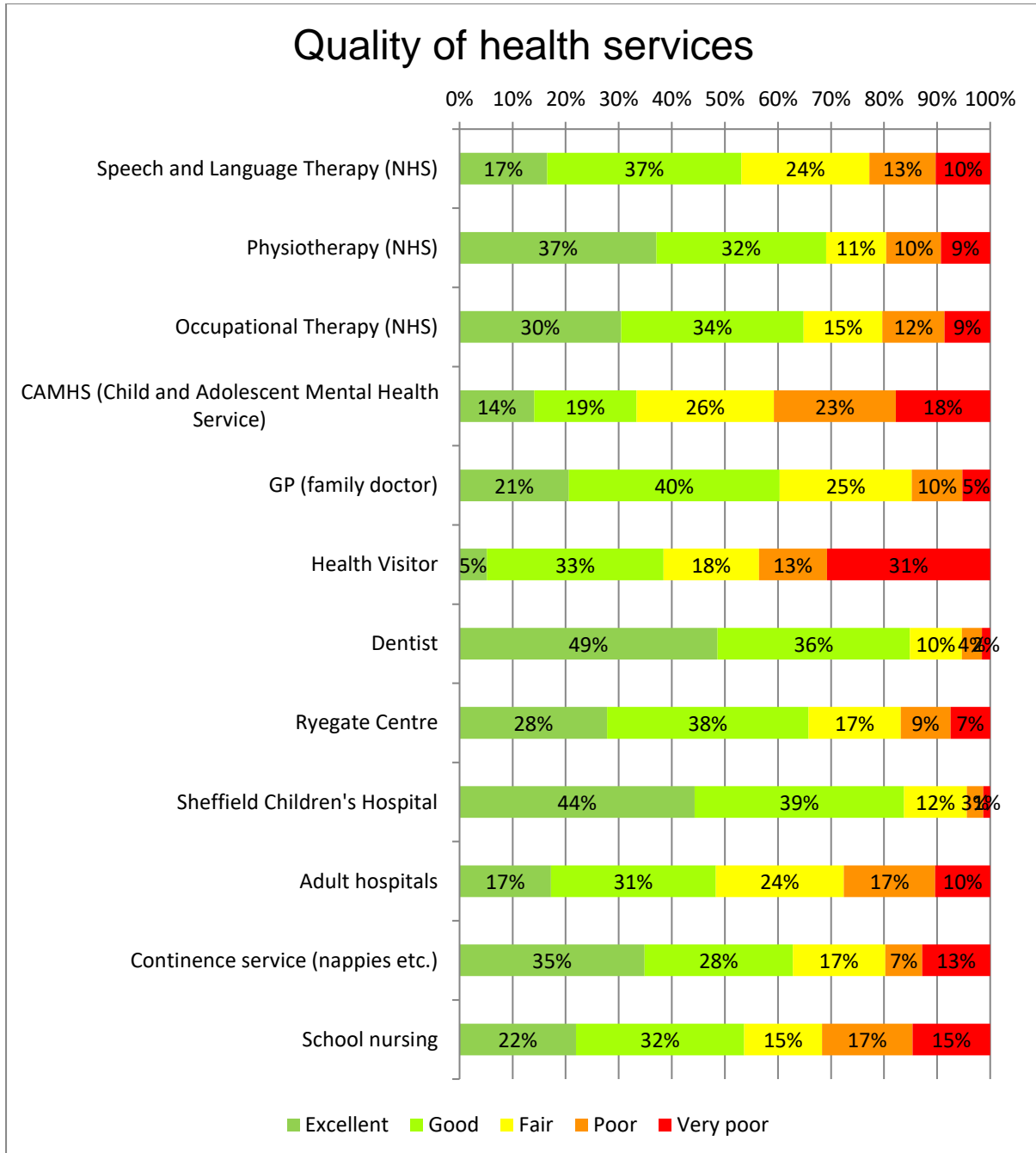
Respondents who are in receipt of a social care service



9. Health services

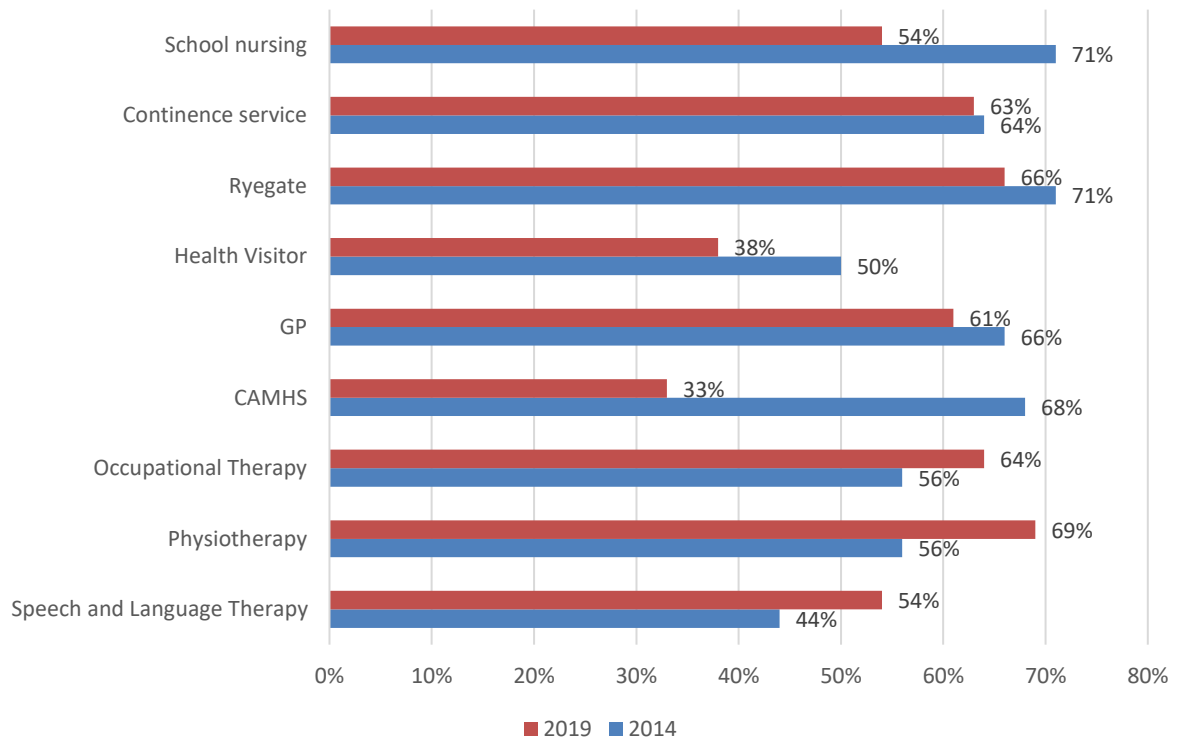
9.1 Quality and quantity of health services (552 responses)

We asked parents to rate health services in terms of quality and quantity.



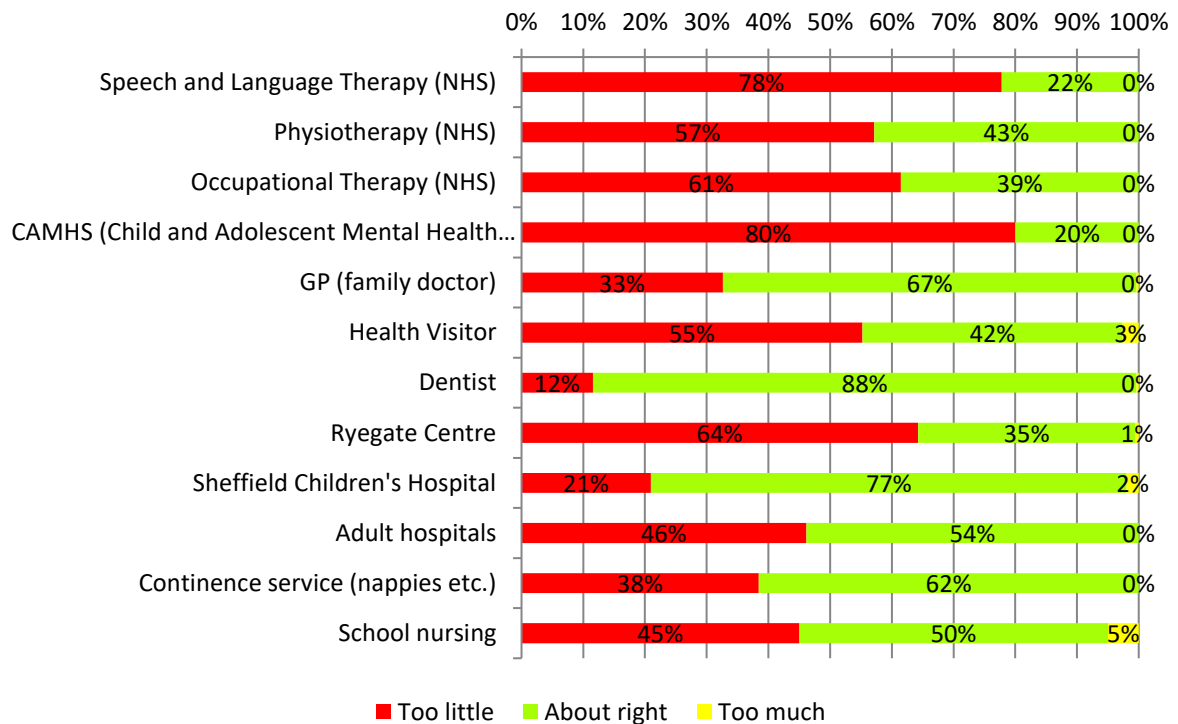
A comparison with quality ratings in our 2014 survey reveals a mixed picture. Whilst the percentage of parents who rated services as “good” or “excellent” had increased for Speech and Language Therapy, Occupational Therapy and Physiotherapy, quality ratings for School Nursing, Health Visiting and particularly CAMHS had seen a sharp decline.

Percentage of respondents who rated services as "good" or "excellent", by year

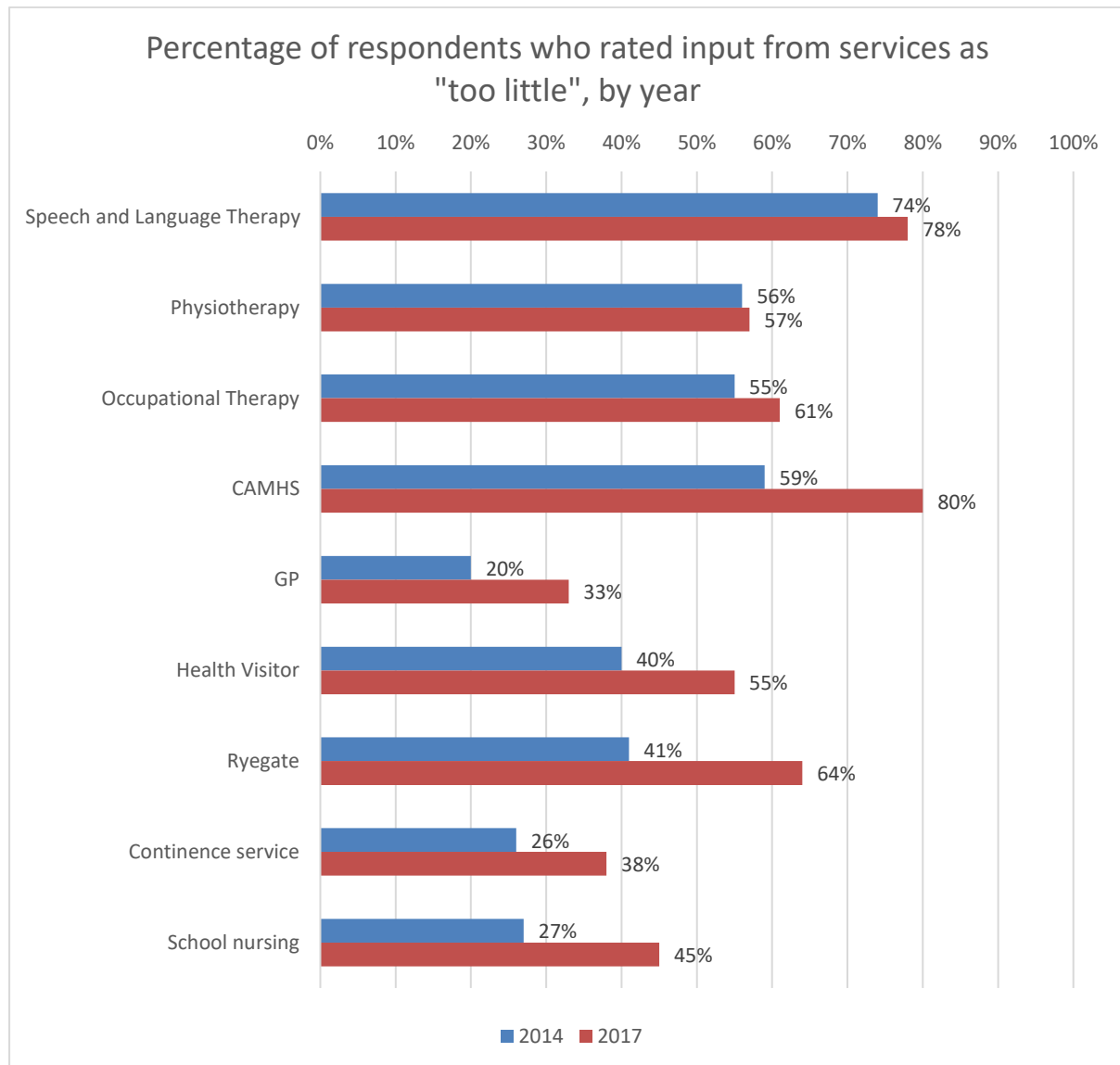


We also asked parents whether their child was getting enough input from health services.

Quantity of health services



We compared the percentage of respondents who stated that their child was receiving “too little” input with responses from our 2014 survey. Whilst those figures had remained high but stable for Speech and Language Therapy, Occupational Therapy and Physiotherapy, there were significant increases for all other services, particularly CAMHS, Ryegate and School Nursing.

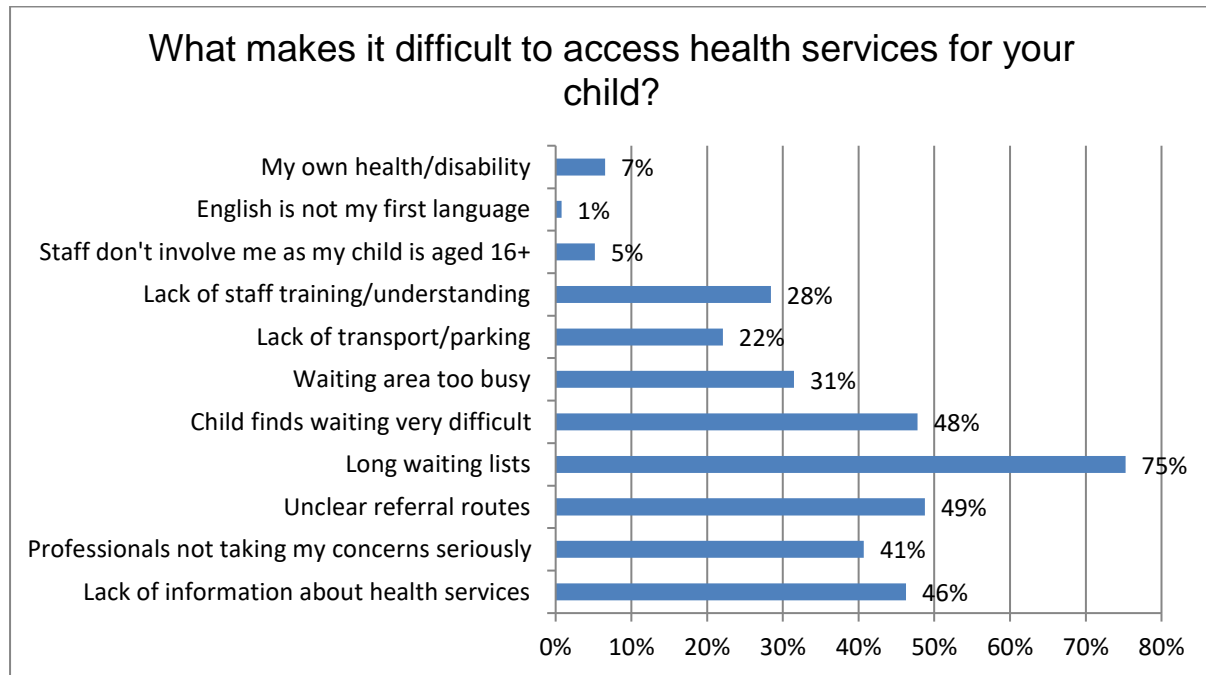


“Speech therapy provision for my child who is four years old and non-verbal is three hours a year.”

“My child needs CBT [cognitive behavioural therapy] for OCD [obsessive compulsive disorder]. 65 week waiting list at CAMHS.”

9.2 Barriers to accessing health services (521 responses)

We asked parents what made it difficult for them and/or their child to access health services:



Respondents who ticked "Other" listed the following issues:

- Lack of joined-up services

"Failure of CAMHS and Ryegate to work together"

- Difficulty getting appointments

"Being bumped off waiting lists for over a year every time we need a Ryegate review. Then have to reach next crisis to be seen and it's still months to be seen."

- Lack of support for complex needs

"Child is predominately housebound /agoraphobic /anxiety etc. CAMHS don't do outreach, GP won't do home visits as my child is viewed as physically capable of attending. Other services not provided yet. In short, nothing happens and as a parent I'm left to manage unsupported."

- Transition to adult health services

"What makes it very difficult to access health services is that she has just moved from children's to adult health services. Gone from having regular appointments with consultants who knew our child well and looked at them and our family more holistically to siloed, fractured, unconnected care. We attended joint transition clinics for two specialities at the Children's Hospital where adult's and children's consultants met together in the same room - very promising. But then we never heard from one of the adult services (at Sheffield Teaching Hospitals) again. This department is central to our daughter's safety and wellbeing - indeed at the Children's Hospital they were the lead consultants for her care."

- Purpose of appointments unclear

“Letters from hospital which don't say which appointment is for what as they have missed out the consultant's name. Have missed appointments as we thought they were for a different consultant!”

9.3 Flu vaccination (598 responses)

We asked parents whether their child got invited to a flu vaccination, via their school or GP. **58%** of respondents said “yes,” **42%** said “no”.

The “No” group included 15 parents of children with a learning disability, one of the high-risk groups covered by the vaccination programme.

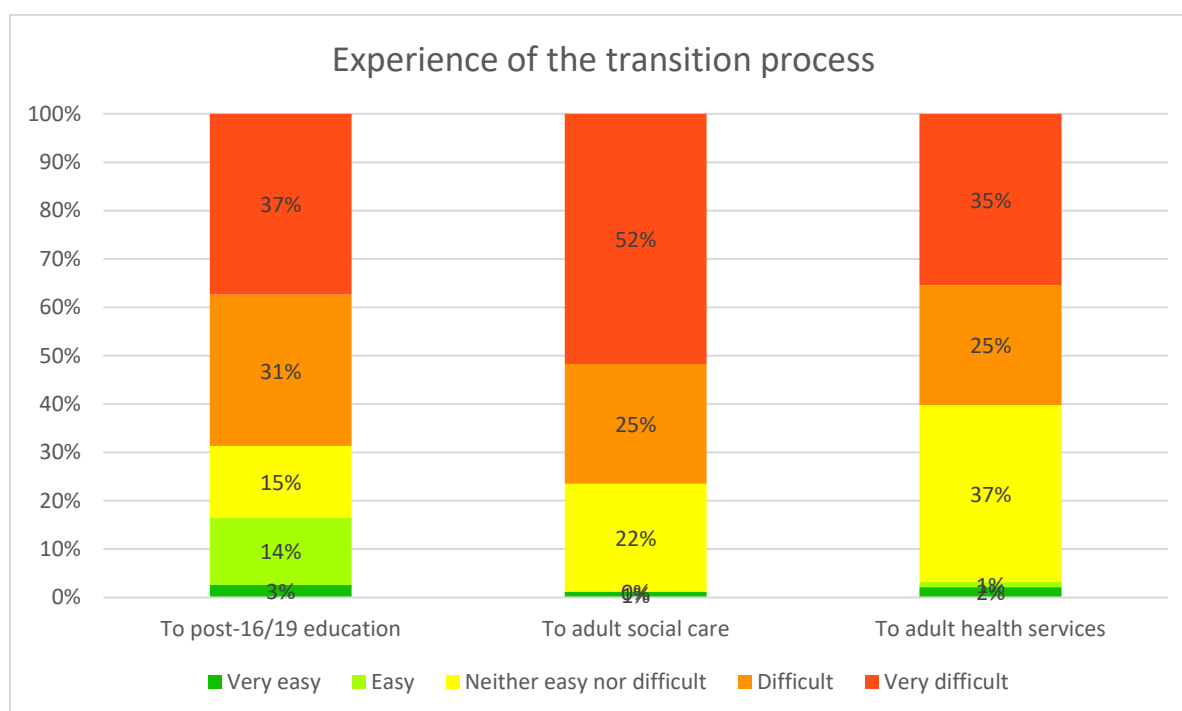
It was not possible to say whether the “No” group also included children aged between 2 and 9 years on 31 August 2018 (who should have all be offered vaccinations). This is because our survey used broader age categories (0-4 years, 5-10 years, etc.).

10. Transition to adulthood

10.1 Experience of the transition process (119 responses)

We asked parents to tell us how they found the transition to post-16/19 education, adult social care and adult health services. All of these transitions were experienced as “difficult” or “very difficult” by a majority of respondents, with the transition to adult social care being rated the most difficult.

N.B. The percentages given relate to the total number of responses for that topic (education: 115 responses, social care: 85 responses, health: 93 responses).



10.2 Information, advice and support in relation to transition (134 responses)

A majority of respondents (55%) said that they had received NO information, advice and support in relation to their child’s transition.

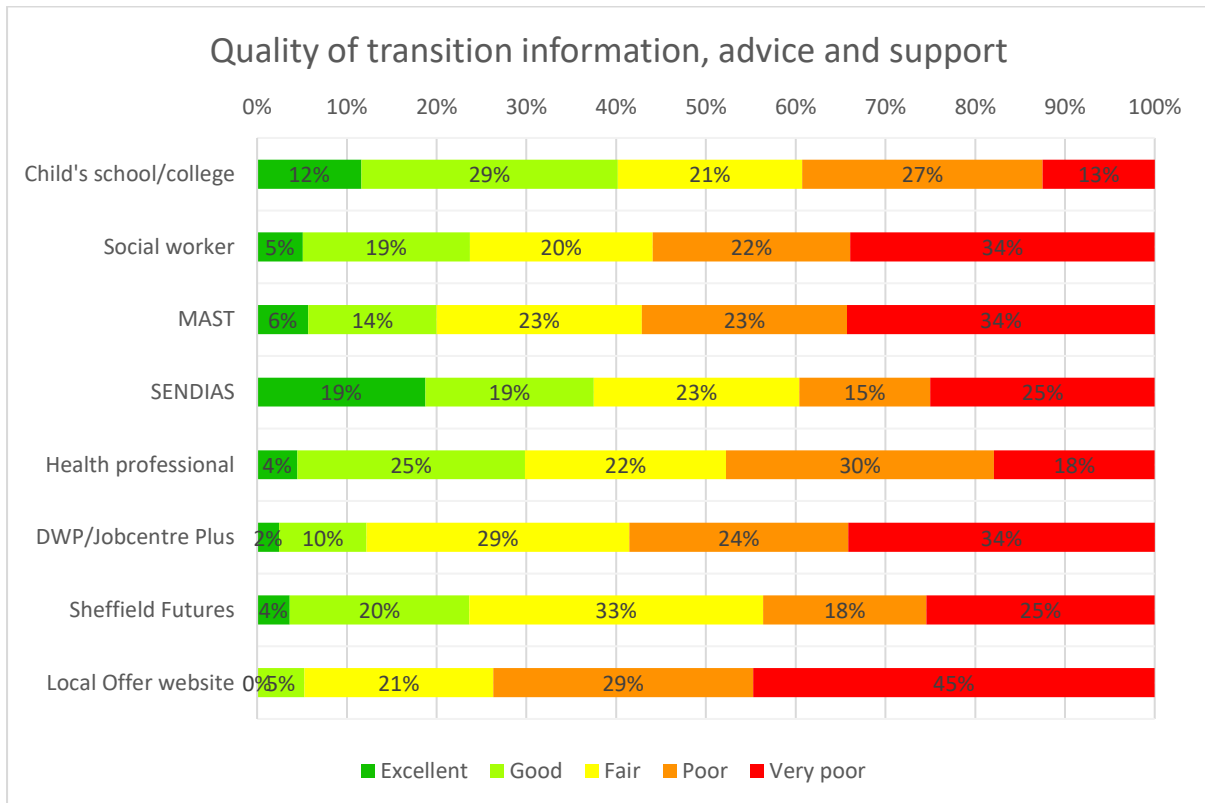
10.3 Quality of transition information, advice and support (128 responses)

The total number of parents who answered this question (128) was greater than the number of parents who said that they had received information, advice and support in relation to their child’s transition (60). It is likely that many respondents equated “poor support” with “no support”.

N.B. The percentages given in the chart below relate to the total number of responses for that particular service. The number of responses differed from service to service.

“There is absolutely no help when a child reaches 16+. If I don’t research and FIGHT, FIGHT, FIGHT. my son would have NOTHING! No one ever instigates assistance or asks how things are going. We all

know that the system is overstretched and we are left feeling 'lucky' for any bone they throw our way. Shameful."



In the free-text comments, respondents highlighted the importance of support received from other parents, third-sector organisations and parent support groups:

"Experts by experience, other parents mainly via SEN social media forums"

"Sharing Caring Project - very helpful"

"Community Learning Disability Team/Intensive Support Service (NHS), other parents and Sheffield Parent Forum"

11. Information and communication

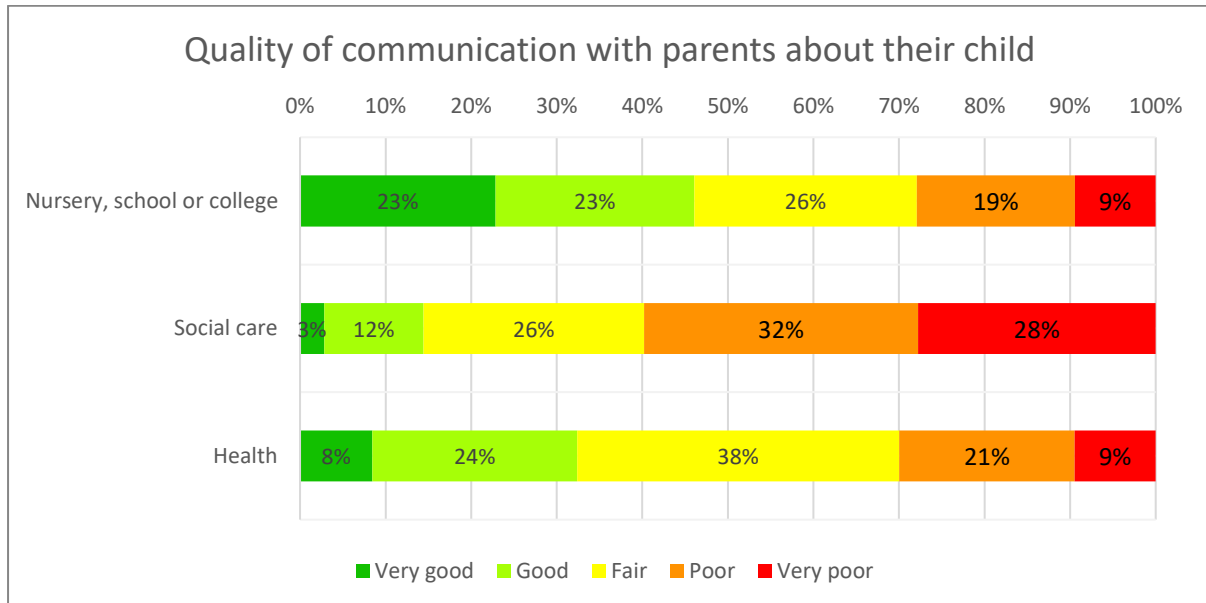
11.1 Quality of communication with parents (593 responses)

We asked parents to rate the communication they have with education providers, health services and social care services about their child with SEND. Although parents' experiences vary widely between providers, overall ratings show that education settings lead the way:

- **46%** of parents said that the communication they had with their child's nursery, school or college was "good" or "very good"; **32%** thought this about health services, and **14%** about social care services.
- On the other hand, **28%** of parents rated the communication they had with their child's education provider as "poor" or "very poor", **30%** thought this about health services, and **60%** about social care services.

"Our social worker is appalling, I have complained about her poor service a number of times and got nowhere. None of the support we have asked for has materialised, she fails to communicate with us at all, e.g. it took five weeks of emails just to order my son a commode."

"My child is happy to attend school and is attaining. I am kept informed of his progress via reviews with the SENCO where his IEP is discussed."

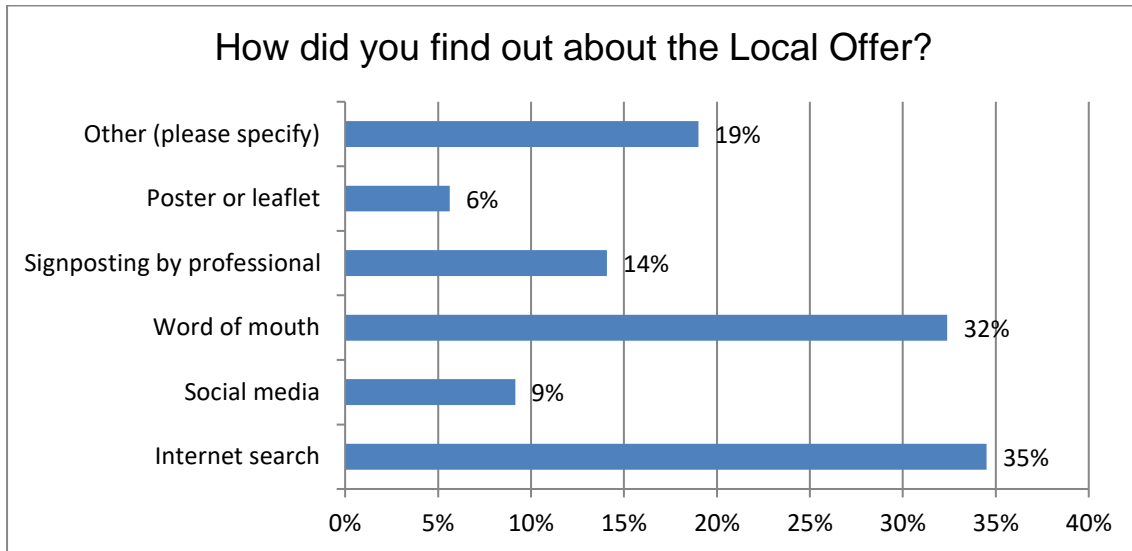


11.2 Awareness of local offer website (590 responses)

22% of respondents had used the local offer website, 78% had not.

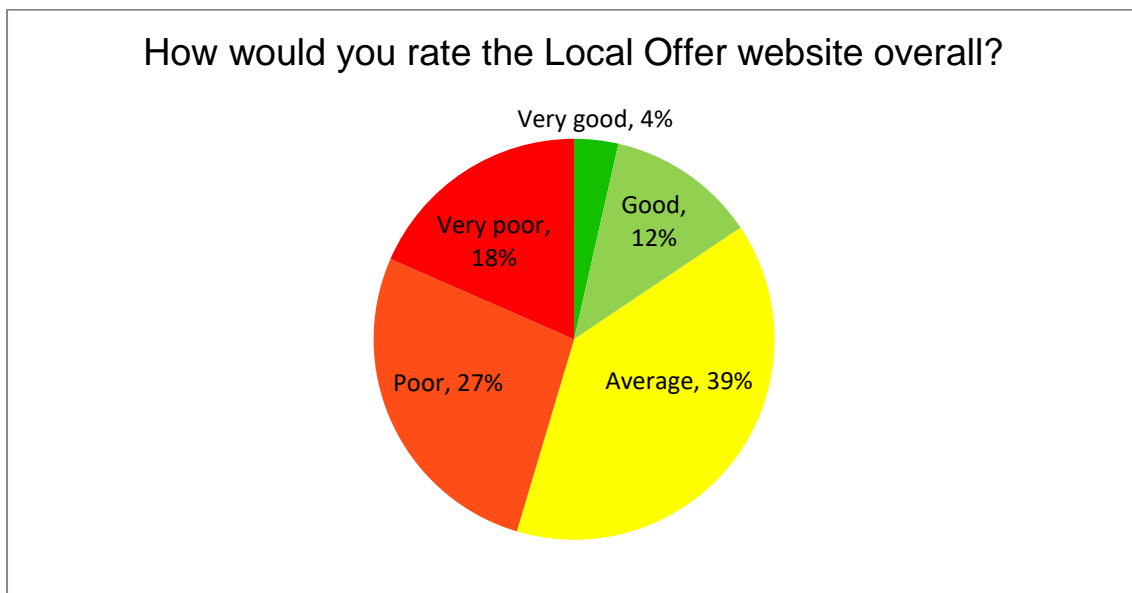
11.3 Finding out about the local offer (142 responses)

Most people had found out about the local offer through internet search (35%) or word of mouth (32%). Most of the respondents who ticked “Other” were either aware of it due to working in this field, or had heard about it through the Sheffield Parent Carer Forum.



11.4 Quality of the local offer website (141 responses)

Almost half of respondents (45%) rated the website “Poor” or “Very poor”.



11.5 Gaps in information (134 responses)

45% said they had found what they were looking for, 55% had not.

We asked respondents to tell us what it was that they had been unable to find. The most frequently mentioned topics were:

- Social care: SNIPS, Short Breaks Grant, Direct Payments, Personal Budgets, overnight respite, social worker assessment, PAs, provision for days when not in college
- Education: EHCP process, schools and their offer
- Childcare: after-school and holiday clubs
- Leisure: sports clubs and inclusive activities

11.6 Ease of finding information (87 responses)

Respondents were split into thirds on this one - 35% thought the information was “Easy” or “Very easy” to find, 36% said it was “Somewhat difficult”, and 30% thought it was “Difficult” or “Very difficult”.



11.7 Was the information clear and easy to understand? (125 responses)

42% said “Yes”, 58% said “No”.

11.8 Was the information up to date? (120 responses)

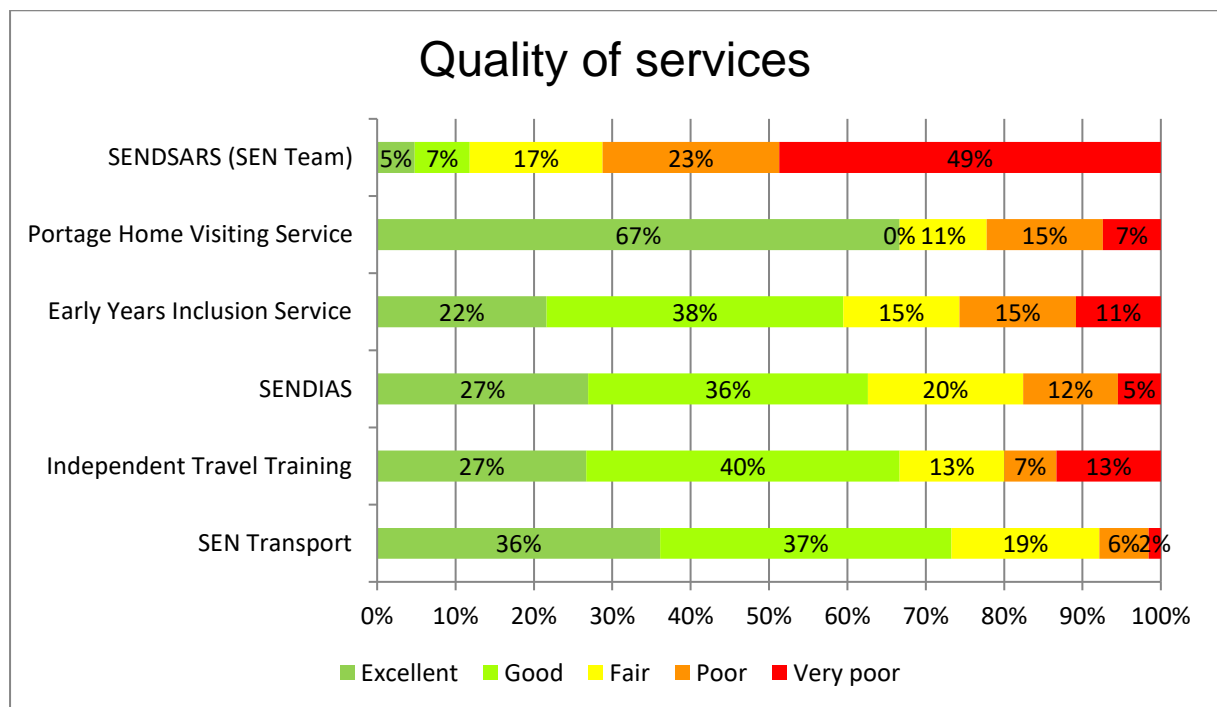
40% said “Yes”, 60% said “No”.

12. General

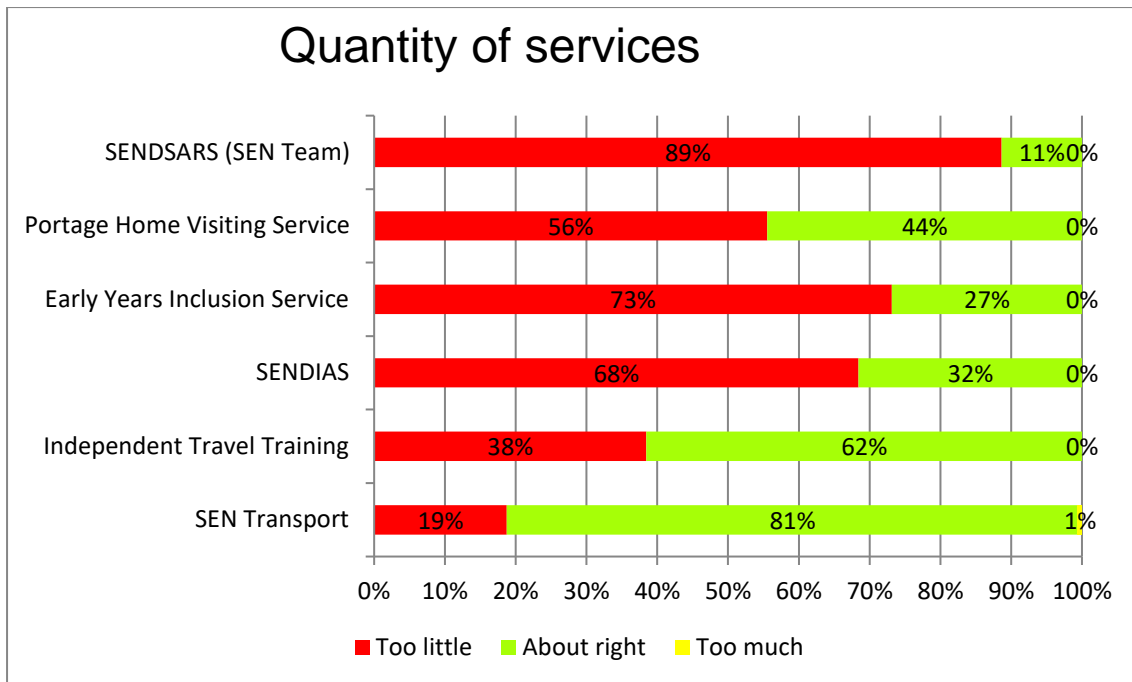
12.1 Quality and quantity of other services (411 responses)

We asked parents to rate the quality and quantity of several services not covered in the previous sections on education, health and social care. Respondents were asked to only rate these services if they had used them in the past **two years**.

N.B. The percentages given relate to the total number of responses for that particular service. The number of responses for some services was quite small (e.g. only 27 people rated Portage, and 45 people rated Independent Travel Training). However, the low quality rating for SENDSARS is based on 271 responses and should give cause for concern.



We also asked parents if they were getting enough of these services (quantity). The responses show that there are significant capacity issues in many services:



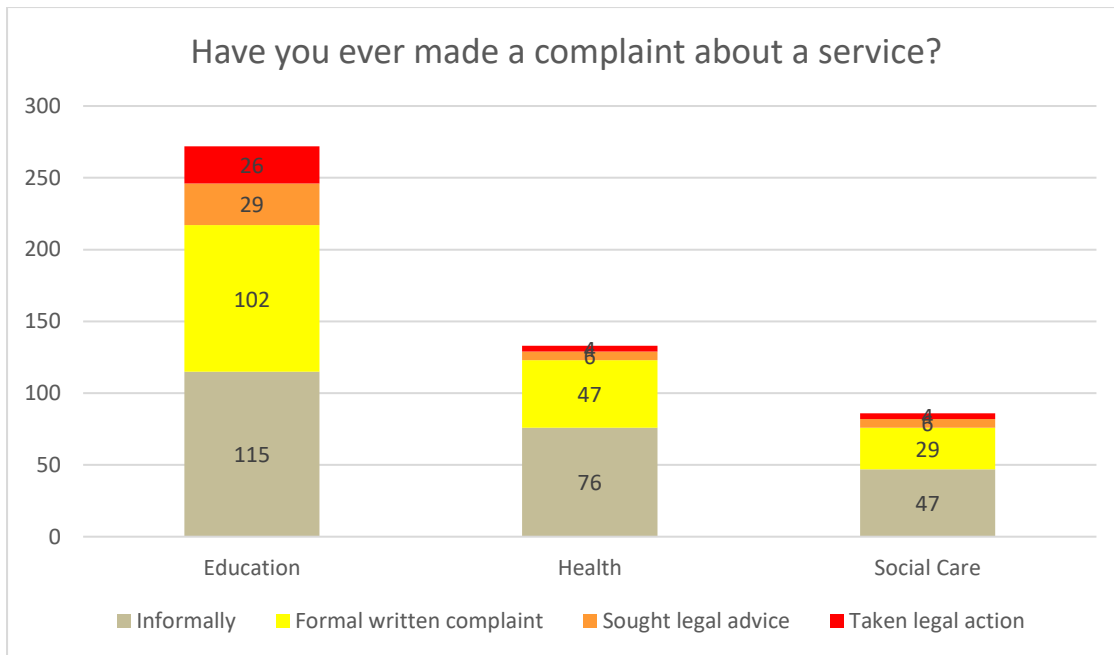
12.2 Complaints (308 responses)

We asked parents if they had ever had to make a complaint about a service, and **44%** of all respondents indicated that they had.

Significantly more parents had complained about education services (272 respondents / 88%) than about health services (133 respondents / 43%) or social care services (86 respondents / 28%). NB Percentages do not sum to 100 as it was possible for respondents to select more than one answer.

The fact that complaints about education are both more frequent and more likely to go down the formal/legal route may be due to the fact that complaints procedures in education are better publicised than in health and social care. For example, schools normally publish their complaints policies on their websites, and letters about decisions relating to EHC plans have to include information on how to appeal against that decision.

NB The table below shows the **total number** (not percentage) of complaints.



12.3 Ease of making a complaint (305 responses)

We asked parents how easy they found it to make a complaint. Over half of respondents said they found this “difficult” or “very difficult”.



12.4 Success of making a complaint (300 responses)

Only **30%** of those who had made a complaint said it had resolved the issue, the remaining **70%** said that it had not. The success rate was higher for complaints about education (30%) and healthcare (27%) than for complaints about social care (20%).

12.5 Services that are needed by not provided (439 responses)

We asked parents if there were any services that their child needed but was not currently getting. **66%** said “yes”.

We asked parents who had responded “yes” to tell us which services these were. There were 303 freetext responses to this question, and the most frequently mentioned services were:

- CAMHS / mental health support
- Social care services
- Speech and language therapy
- Support in education
- Occupational therapy / Physiotherapy
- Health services and assessments
- EHCPs: getting an assessment, or implementing an existing EHCP
- Educational Psychology
- Leisure activities
- Autism Service
- Sensory support
- Specialist placement
- Support to become more independent

Other services – all mentioned by several respondents – included: support for emotional wellbeing, transport, transition to adulthood, general help and advice, and continence service.

12.6 Examples of good practice (192 responses)

We asked parents to give us examples of good practice that we could share. **27%** of all respondents answered the question. However, **31%** of these did not provide any good practice examples and instead gave examples of poor practice and/or suggestions for improvements.

A large number of respondents mentioned specific members of staff who had gone above and beyond the call of duty. Parents expressed a huge gratitude towards these people. We plan to contact them individually and ask for their permission to share this feedback.

When describing the positive contributions made by staff, parents repeatedly mentioned a number of specific traits:

- Communicates well with parents
- Gives advance warning of changes
- Approachable
- Proactive
- Compassionate and caring
- Honest and transparent

- Non-judgemental
- Responds quickly
- Treats parents as equal partners
- Supports the whole family
- Flexible / accommodating
- Believes the child/parent
- Works in a person-centred way
- Understands the child's disability

Many respondents praised **specific services**:

- **Health services:** "Ryegate" got by far the most mentions; within this, the Occupational Therapy and Physiotherapy Service was singled out for particular praise. The Speech and Language Therapy Service and the Sheffield Children's Hospital were also cited as good practice examples by numerous respondents. Several parents said that the support and training for school staff provided by nurses (e.g. ADHD nurses, Epilepsy nurses) had been hugely beneficial for their child.
- **Local Authority services:** Several parents praised the SEN Transport Service, Portage and SENDIAS.
- **Social Care services:** Several parents said they had had excellent support from a transition social worker. There were a few mentions other services, such as children's respite care homes, ibk initiatives and MAST.
- **Voluntary sector organisations:** Parents mentioned a range of voluntary organisations, such as ACCT, Ray of Hope, Sheffield Parent Carer Forum, SHEDS and Mencap.
- **Settings:** Most of the special schools and Integrated Resources in Sheffield were mentioned, as were a range of mainstream schools, colleges and nurseries.

Other good practice examples included:

- **Training for parents:** Examples include the post-diagnosis workshops at Ryegate, Cygnet course, ADHD workshop at Silverdale, training provided by Portage.
- **Training for staff:** Several parents mentioned training and support for school staff provided by the ADHD and Epilepsy nurses and outreach provided by Mossbrook.
- **Good transition support:** Examples include staff doing home visits before starting school, good support from transition social workers, DSD "Moving on" course, teacher preparing class for maternity leave, extra transition visits and summer school before starting in Y7, secondary teacher visiting child in primary school, helpful speech and language assessment and staff training in Y6, good information sharing between schools, training and support for secondary school staff provided by Epilepsy nurse.
- **Having a keyworker**
- **Good communication between services,** e.g. Ryegate communicating child's needs to GP and school in a clear manner, Integrated Down Syndrome Clinic at Ryegate run by Dr Harrower, Dr Harrower and ADHD team working well together, Care Programme Approach to coordinate agencies involved in young person's transition to adult services.

13. Conclusions and next steps

This survey investigated the views of parents of children and young people (aged 0-25 years) with special educational needs and/or disabilities in Sheffield.

It repeated many of the questions we had posed in a previous survey, back in 2014. This enabled us to assess how parental satisfaction with local services has changed since the introduction of the Children and Families Act 2014 and the Care Act 2014.

We found that on most fronts, things have become worse:

- **More families report that they feel isolated and are struggling to cope.** More parents say that they are not getting enough support from social care services.
- **Key services for children with SEND are stretched ever more thinly.** For some services, as many as **90%** of parents are now saying that their child is getting “too little” input. It is likely that capacity issues in NHS services are impacting on the time it takes to get an assessment – many families had to wait for over a year, and some for two or three years.
- **Three quarters of the children in our sample were affected by anxiety and/or depression,** yet parents report great difficulties in accessing mental health services.
- **EHC plans are not working as intended.** These plans were meant to create a more holistic and person-centred approach to meeting the needs of the most complex children – yet most parents described the process of applying for an EHC plan as difficult. Parents also expressed concerns about the quality of plans, particularly for statement-to-EHCP conversions. Quality issues could be addressed through the annual review process; however, our survey found that this process is often non-compliant with statutory requirements. And even the best-written plans are of limited use if they are not being properly implemented – which our survey found to be a widespread problem.
- **Children with SEND in mainstream settings are bearing the brunt of many years of real-terms funding cuts.** In 2014, almost **half** of all parents of mainstream pupils thought that their child’s needs were being met by their child’s school; in 2019, this had fallen to just a **quarter**.

To introduce large-scale system change at a time of austerity was always going to be problematic, and our survey bears this out. The SEND reforms have raised families’ aspirations, but successive cuts to local authority and school budgets alongside increasing demand have made these very hard to achieve. Mainstream schools and colleges have been further disincentivised from promoting inclusion by an education policy that prioritises academic attainment above all else.

In 2016, the government introduced a regime of SEND inspections, designed to assess how well local areas are implementing the SEND reforms. Sheffield was inspected in November 2018, and was told to produce an action plan to address a number of significant weaknesses. We will work with the local authority and Sheffield Clinical Commissioning Group to ensure that the findings from our survey are reflected in this action plan, as well as in Sheffield’s overall SEND strategy.

There are many areas where relatively inexpensive changes could make a big difference – for example, through improved information and communication, more training for staff and parents,

and more effective pathways and processes. Such changes will only be effective if they are **coproduced** with children, young people and parents.

We recognise that where the system still works well for families, this is often due to the committed professionals and practitioners who go the extra mile. Their good will is not an unlimited resource.

Government funding cuts have caused many of the harmful trends we are now seeing, and long-term funding increases are needed to reverse them. However, there is much that Sheffield City Council, NHS Sheffield Clinical Commissioning Group and providers of education, health and social care services can do to alleviate the issues highlighted in this report. We will continue to provide constructive challenge and push for this to be done.