



State of Sheffield

Executive Summary

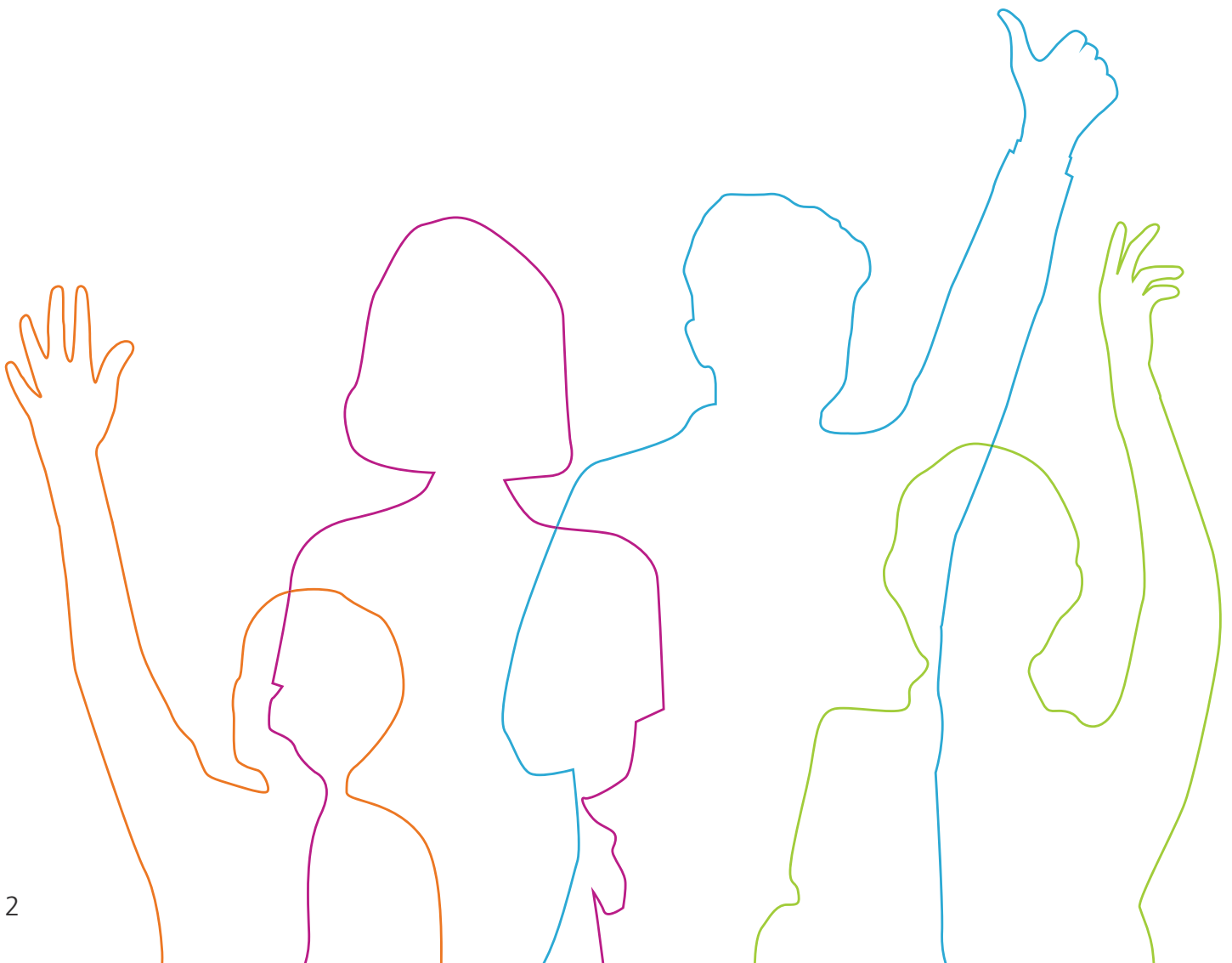
March 2019

The views of parents and carers of children and young people with special educational needs and/or disabilities (SEND)



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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 findings 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.

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.

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 during a SEND inspection in November 2018.

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

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. We also asked local parent support groups, BME organisations, Family Centres, schools and colleges to publicise the survey to parents.

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 who were 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 Education Health and Care (EHC) plan and **21%** had a My Plan.

706
responses were received



Identification and assessment of needs

Many parents had to wait a long time to get their child's needs assessed.

58% had waited more than a year for an assessment, and **30%** had waited more than two years. (NB We did not ask parents how long ago their child was diagnosed, so this may include pre-2014 data.)

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 meeting their needs.

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

"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."

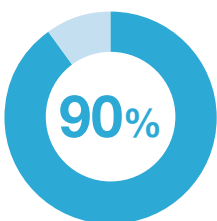
We found that children with a wide range of diagnoses often have very similar needs. Problems with social interaction affected **90%** of the children in our sample, **86%** struggled with sensory processing difficulties (e.g. oversensitivity to noise or smells, sensory-seeking behaviours, restricted diets due to aversion to food textures), **83%** displayed challenging behaviour, **81%** had sleep issues and **76%** were affected by anxiety and/or depression. It was very common for children to have difficulties in more than one area.

However, commissioning decisions are usually driven by diagnosis rates rather than needs. This can make it difficult for children who do not have a diagnosis, or who do not meet the threshold for the service that caters for their particular disability, to get the support they need.

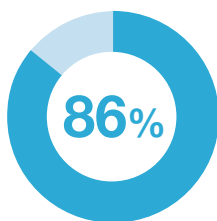
Most conditions can only be diagnosed by a health professional. Parents told us that the biggest barriers to accessing health services for their child with SEND were long waiting lists (**75%**), unclear referral routes (**49%**) and a lack of information about health services (**46%**).

A diagnosis is often essential for accessing services. However, it tells us very little about how a disability affects an individual in their everyday life.

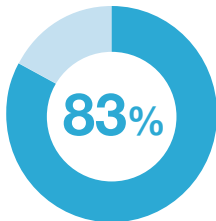
"My child has developmental language disorder. Despite seeking assessments from age 6 this wasn't diagnosed until age 9, not a well known/understood condition. Wish my child had more widely recognised issue e.g. dyslexia, suspect it would be easier to access support."



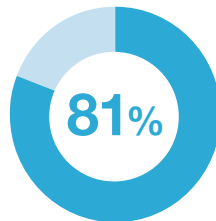
of the children in our sample had problems with social interaction



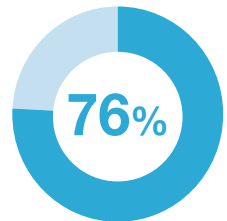
struggled with sensory processing difficulties



displayed challenging behaviour



had sleep issues



were affected by anxiety and/or depression



Social inclusion

Families with children with SEND experience high and increasing levels of isolation.

Over **60%** of respondents told us that they found it “difficult”, “very difficult” or “impossible” to take part in everyday activities as a family, such as visiting friends or relatives, going out for a meal or going on holiday.

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%**).

82% of parents reported that their child with SEND was “sometimes” or “frequently” left out of social activities, e.g. not invited to birthday parties.

Social care services like short breaks are vital for reducing the isolation experienced by children with SEND:

“My daughter has two befrienders through SNIPS and ibk. Both are invaluable support to her accessing activities without parent present. This is much needed, as she has no one in her peer group to attend activities with, as she is at a special school.”

37% of parents had given up work in order to cope with their caring responsibilities. These parents are doubly disadvantaged, as they miss out on social contacts with co-workers and have less money to participate in leisure activities.



Impact on siblings

83% of respondents said 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%**).

“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.”

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

Having a sibling with SEND increases children’s risk of isolation. Almost a third of parents said that siblings were missing out on activities (e.g. sports clubs or social events) or could not have friends over. **34%** of parents reported that siblings felt resentful towards their brother or sister with SEND.

Short breaks are essential for ensuring siblings get to spend quality time with their parents.

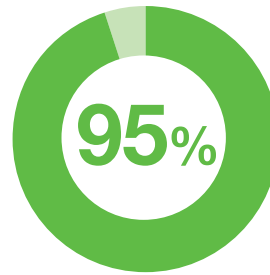
“We need more holiday and weekend provision to allow our child [with SEND] to take part in activities and clubs and to allow his siblings to be able to access more activities and benefit from our attention.”



Impact on parental wellbeing

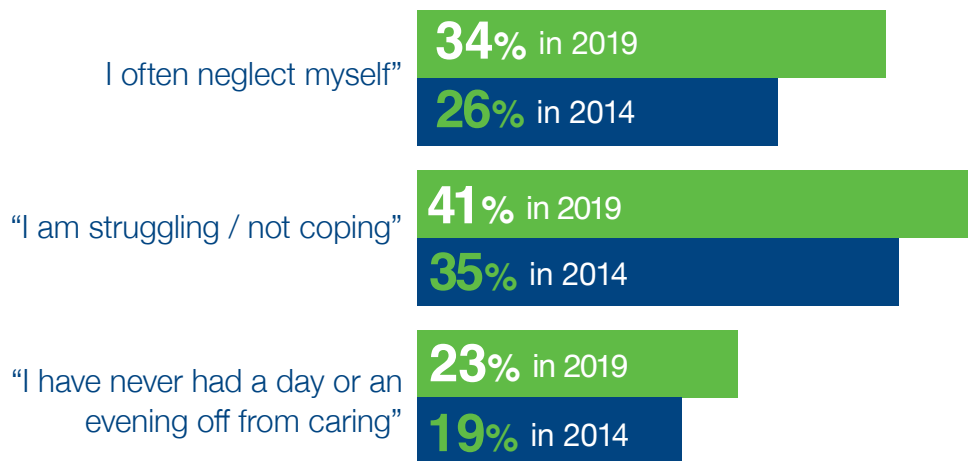
95% of parent carers reported that caring had affected their wellbeing, particularly their emotional wellbeing, their sleep and their relationships. **64%** also reported a negative impact on their mental health, and **53%** said that caring had affected their physical health.

Compared to our 2014 survey, there was a marked increase in the percentage of parents who reported a negative impact on their mental health (from **49%** to **64%**).



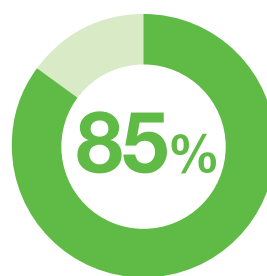
of parent carers reported that caring had affected their wellbeing.

Other figures also suggest that pressures on parent carers are increasing:



57% of the parents who said they were "struggling" or "not coping" were not receiving any support from social care services.

Many of the families surveyed faced additional pressures. **19%** of parents had a disability or long-term illness themselves, **29%** had more than one child with SEND, **16%** also provided care for an adult over the age of 25, and **22%** were one-parent families.



of respondents said they wanted training to help them cope with the demands of caring for their child with SEND

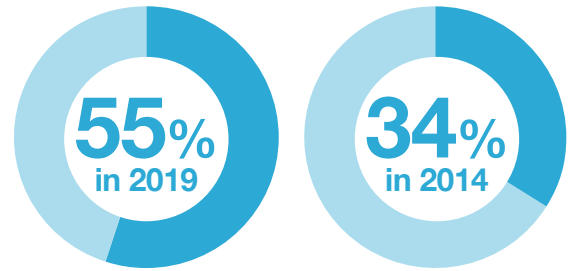
"The assessment criteria [for social care services] do not allow for a combination of factors to contribute to a complex whole. [...] When combinations of concerns are put forward, the response is to dismiss our case as too complex. When issues are looked at individually, our case is dismissed as not severe enough to merit support."

Their top priorities for training were: supporting their child's emotional wellbeing and mental health; understanding the SEN system and their rights as carers; managing challenging behaviour; coping with stress; and helping their child with sensory issues.



Support from social care

We asked parents whether they thought that their family's social care package was enough to meet their needs. **55%** said that it wasn't. This is a significant increase from 2014, when this figure stood at **34%**.



The percentage of parents who thought that their family's social care package was insufficient to meet their needs.

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

"Tried accessing SNIPS, they didn't listen to our needs. Can't get a MAST worker due to school and paperwork. The whole system is stacked against parents who are already up against it all as they fight NOT to give help, even the little things that would make a vast difference to us. It's exhausting."

Many parents said they received no support from social care, and had no idea what was available or how to access it. Those who had applied for support often described a long and complicated process.

"It is inflexible. The assessment criteria lacks transparency. When we were awarded funds it was too little too late. By the time the appropriate funding arrived (the amount we were originally assessed as needing) I had had an unnecessary physical breakdown."

"We have NEVER had a social care assessment for our family despite have three children with special needs in our family. Two have high needs and have EHCPs, neither were given a social care assessment as part of their statutory assessments. We have no respite at all."

52% of the families who currently receive a social care service said that the recent changes to the Short Break Grant and SNIPS clubs would have a "significant" impact on them.

"We have lost short breaks this year with the new criteria. This was invaluable to us being able to access a week away together. I can't afford a holiday without it and I think this will affect both of our mental health need."

Parental satisfaction with social care services varied widely between services

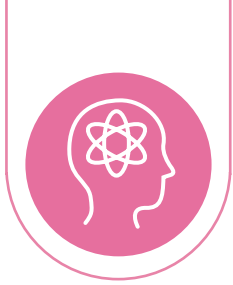


Almost half of respondents rated adult social care, the Children with Disabilities Team and MAST intervention workers as "poor" or "very poor".



Other services, such as overnight respite or the Short Break Grant, received predominantly positive ratings.

We did not ask parents to rate social care services in our 2014 survey, so there is no baseline to compare these ratings against.



Mental health and emotional wellbeing

Survey responses highlight an acute and often unmet need for mental health support.

12% of the children in our sample had a primary need of Social, Emotional and Mental Health Difficulties. However, this does not reflect the high incidence of comorbid mental health difficulties in children with other diagnoses. **76%** of the parents in our sample said that their child with SEND was affected by anxiety and/or depression. Around half of these children were reported to be “severely” affected.

80% of parents said that their child was not getting enough input from CAMHS. When asked whether there were any services that their child needed but wasn’t currently getting, CAMHS and mental health support topped the list.

Compared to our 2014 survey, there was a marked increase in the percentage of parents who said that caring for a child with SEND was having a negative impact on their own mental health (from **49%** to **64%**).

43% said that having a sibling with SEND was impacting on the mental health and/or emotional wellbeing of their other children.

When we asked parents about their training needs, “supporting my child’s emotional wellbeing or mental health” was the most requested topic. We are not aware of any training around this topic that is open to all parents of children with SEND.

“My son is in desperate need and has been for 4 years, we waited over 2 years for diagnosis and have been warned we will wait 2 years for a psychology appointment, this is despite our consultant putting his need as urgent. My son has wrapped a dressing gown cord round his neck and pulled it saying he wants to die and I can’t get him help for 2 years! This is a total disgrace! I have to watch him like a hawk and have cobbled together my own therapy programme for him. If I was not in the educated position to do this I genuinely think my son would be totally mentally damaged or dead. This is appalling and heartbreaking.”

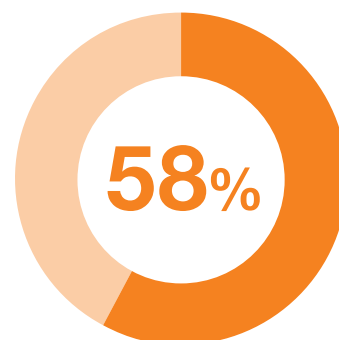


Work and finances

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). It is possible that benefit cuts are forcing more parents to work.

37% of respondents had given up work to cope with their caring responsibilities, **36%** had reduced their hours and **26%** had taken a less challenging job.

We found that fewer parents were in receipt of means-tested benefits than five years ago (**45%** in 2019, compared to **57%** in 2014). This could be a consequence of cuts and restrictions to benefit entitlements, parents increasing their earnings and/or work hours, or both.



of parents said that their family was worse off as a result of caring for their child with SEND.



Education

Compared to our 2014 survey, parental satisfaction with mainstream education had decreased significantly. In 2014, **47%** of mainstream parents said that their child's school was adequate for meeting their needs. In 2019, this figure had halved to **24%**.

Where parents rated mainstream provision as inadequate, this was mainly due to insufficient support, expertise and understanding, the negative impact this was having on the child's mental health and emotional wellbeing, and poor communication with parents. Many parents said that their child's support had decreased due to school funding cuts.

"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?"

Part-time timetables were not unusual. We 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.

Many 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."

"They have no understanding that things may appear ok at school but when T gets home he struggles with the build-up of emotions from the day and replays everything for weeks. No support has been put in place at school despite the fact that academically the gaps are beginning to show and socially they are widening."

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.

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.

Views about **Integrated Resources** were mixed. Some parents said these units had become overcrowded and understaffed.

Bullying affected a large number of children, particularly in mainstream schools and Integrated Resources (IRs). **63%** of respondents said that their child had "sometimes" or "frequently" been bullied by other children. This represents a **10%** increase against our 2014 survey.

Just 24%
of mainstream parents said that their child's school was adequate for meeting their needs



Childcare

Three quarters of respondents said that it was “difficult”, “very difficult” or “impossible” to find childcare for their child with SEND.

83% of parents said that caring had affected their ability to work. **38%** of these parents said they had been unable to find suitable childcare for their child with SEND, and **25%** said they couldn't afford it.

Relatively few families in the survey used formal childcare for their child with SEND, with **48%** relying on family members, friends and neighbours instead. However, the percentage of families who used formal childcare was higher than in 2014.

When asked if there were any services that their child needed but wasn't getting, many parents mentioned after-school clubs and holiday clubs.

“We will need more after-school club cover as our daughter moves to secondary school as we no longer have access to after-school clubs and we both work full-time. Also, we have to use our PA payments to cover after-school and so little to nothing left for any respite for us as parents at weekends.”



Education Health and Care (EHC) plans

77% of respondents who had applied for an EHC plan said that they found the process “difficult” or “very difficult”. Conflicts over EHC plans were often exacerbated by a lack of special school places.

Parental feedback about SENDSARS (SEND Statutory Assessment and Review Service – the team that deals with EHC plans and specialist placements) was largely negative. **71%** of respondents said that the service provided by SENDSARS was “poor” or “very poor”, and **89%** reported that there wasn't enough of it.

“I had to appeal against an EHCP for another child, because we thought the EHCP and the school placement on it was inappropriate and against our stated wishes. The whole process seemed set up to try and get parents to give up and accept SEND's position. Sheffield should be ashamed that they have created a process designed to maximize anxiety and distress. You do not need that on top of having to deal with children attempting to kill themselves or you.”

An EHC plan is a formal legal document which places a statutory duty on the local authority and the Clinical Commissioning Group to arrange the special educational and healthcare provision described in it. **However, only 13% of parents of children with EHC plans reported that their child's plan was being fully implemented.**

“No support for kids with anxiety or autism e.g. a breakout space, even though it is in my son's EHCP. SENCO is useless and not taking EHCP seriously.”

“Mainstream state school not supporting as per EHCP. Lies from school stating they are and LA not chasing provision in section F.”

Parental feedback about the annual review process indicates that neither schools nor the local authority consistently meet their statutory obligations:

- **32%** of parents said that their child's EHC plan had not been reviewed in the past 12 months.
- **67%** had not received reports at least two weeks before the review meeting.
- **57%** had not received a letter about the outcome of the review within four weeks after the meeting.



Parental satisfaction with services

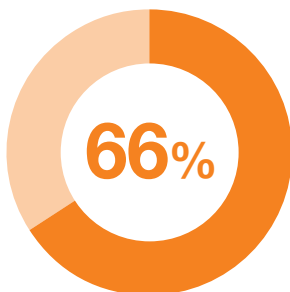
In 2014, parents highlighted significant capacity issues in a number of key services accessed by children with SEND. In 2019, all of these services had seen a deterioration in capacity ratings.

For the lowest-performing services in 2014 - Educational Psychology, the Autism Team and Speech and Language Therapy – capacity ratings had decreased even further in 2019.

Several other services seem to be heading in the same direction. The biggest falls in capacity ratings were recorded for CAMHS, the Ryegate Children’s Centre, the Vision Support Service and the Becton Outreach Team.

Quality ratings also fell for most of the services we looked at. This was particularly pronounced for education support services, where the percentage of respondents who rated them as “good” or “very good” had fallen across the board, by around **30%** for most services.

The picture for health services was more varied. Whilst Speech and Language Therapy, Occupational Therapy and Physiotherapy had seen an improvement in quality ratings, other services – like School Nursing, Health Visiting and particularly CAMHS – had seen a sharp decline.



of parents said that there were services that their child needed but was not currently getting

We asked parents if there were any services that their child needed but was not currently getting. **66%** said “yes”, **34%** said “no”. The services most frequently reported as missing were CAMHS and mental health support, social care services, speech and language therapy, support in education and occupational therapy and physiotherapy.

“We have nothing ... no support. We pay for specialist tuition (so my daughter can understand and actually participate in her class) and psychotherapy once a week (we fear she will have a mental breakdown or worse, suicide). We have had to take out loans to pay for the above which comes to approximately £100 per week.”

“When my daughter was struggling a few years ago I was desperate and couldn’t get through to the Autism Team. This was a very hard time.”

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

“Educational psychology - we have asked and told not needed by school. Paid for private assessment. Processing speed on 1st centile found. Still denied Ed psych input at school.”

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

Overstretched services

The percentage of parents who said their child was getting “too little” input from these services:





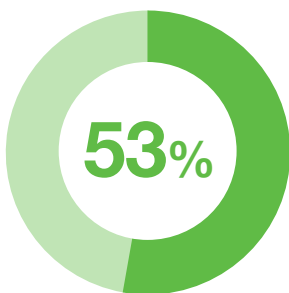
Transitions

Transition to secondary school

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.”



of respondents found the transition from primary to secondary school “difficult” or “very difficult”

Transition to adulthood

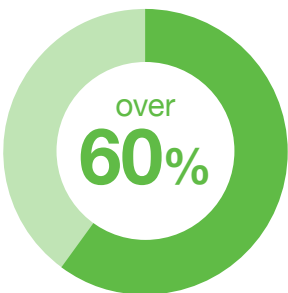
Over **60%** of parents experienced the transition to post-16/19 education, adult social care and adult health services as “difficult” or “very difficult”. The transition to adult social care was regarded as the most difficult.

Many parents felt unsupported during the transition process, with **55%** stating that they had received no information, advice and support at all.

“I am left without any package due to the transition from children’s services to adult services. Very poor service. Shocking”

We asked those parents who had received help with transition to rate the service that provided it. Only school/college and SENDIAS were rated “good” or “very good” by at least a third of respondents. Social workers, MAST, DWP/Jobcentre Plus and the local offer website were rated “poor” or “very poor” by over **50%** of respondents.

“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.”



of parents experienced the transition to post-16/19 education, adult social care and adult health services as “difficult” or “very difficult”



Communication and information

Communication

One of the reasons that parents often give for being dissatisfied with services is “poor communication”. So who does this well?

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:

Responses highlight high levels of variability:



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.

“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.”

“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.”

Information

Being given the right information, at the right time, can have a significant impact on parents’ ability to cope. Without this information, families miss out on early support and often only come to the attention of services when problems have become entrenched.

“No one has a definitive answer to routes, procedures and access to information. I feel left in the dark – was given a diagnosis and then left.”

The local offer website was launched in 2014. It is intended to provide a one-stop shop for information about support and services for children and young people with SEND.

Our survey shows that awareness of this website is still low, with **78%** of parents reporting that they had never used it. Most of the parents who had accessed the site had found it through internet searches or heard about it through word of mouth.

45% of them rated the local offer website as “poor” or “very poor”.

55% said that they had not been able to find the information they were looking for. In some cases, this was because the information was missing; in others, because it was too difficult to find.

Of the parents who did manage to find what they were looking for, only around **40%** thought that the information was clear, easy to understand and up to date.

Sheffield City Council has commissioned the Sheffield Parent Carer Forum to update, improve and develop the local offer website. Due to a number of technical and procedural challenges, this work got off to a slow start. However, the pace of change is improving, and the feedback from this survey will provide a useful baseline against which to measure progress.

Sheffield **SENDIAS** (SEN Information Advice and Support) is an important advisory service for parents of children and young people with SEND. **63%** of parents rated this service as “good” or “very good”. However, **68%** said that there wasn’t enough of it.

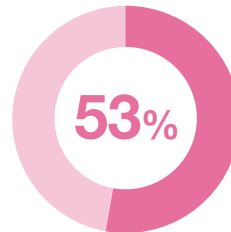


Complaints

44% of the parents in our sample had complained about a service. This includes informal (verbal) complaints, formal written complaints and legal action.

Complaints about education were far more frequent than complaints about health or social care services, and they were also more likely go down the formal/legal route. This may be due to the fact that complaints procedures in education are better publicised than in health and social care.

The success rate was low, with only 30% of parents reporting that making a complaint had resolved the issue. Complaints about social care were less likely to be successful than complaints about education and healthcare.



of parents said that they found it “difficult” or “very difficult” to make a complaint.



What works?

When parents talk about good practice, they don't usually mention systems and processes, but focus on people instead. **Many parents told us about individual members of staff who had gone above and beyond to help their child and their family.**

When describing the positive contributions made by these members of 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 also praised specific schools and services, including a range of NHS and local authority services, voluntary sector organisations and parent support groups.

Where respondents were specific in their praise, some common themes emerged

- Training for parents and staff was valued highly. This was particularly effective if it was provided by specialists in relation to an individual child, e.g. epilepsy nurses providing ongoing training and support for school staff.
- Good support around transitions made a big difference.
- Having a keyworker was very helpful.
- Parents valued joined-up services, especially where one professional or service takes on a coordinator role.

Many parents told us about individual members of staff who had gone above and beyond to help their child and their family.



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 access to mental health support was reported to be poor.
- **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.



For questions or comments regarding this report, please contact:

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The full report

To access the full version of this report, please go to:
www.sheffieldparentcarerforum.org.uk/about/publications

Acknowledgements

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

About the Sheffield Parent Carer Forum

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

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