

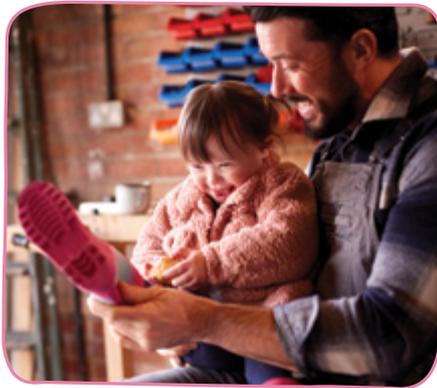


State of Sheffield



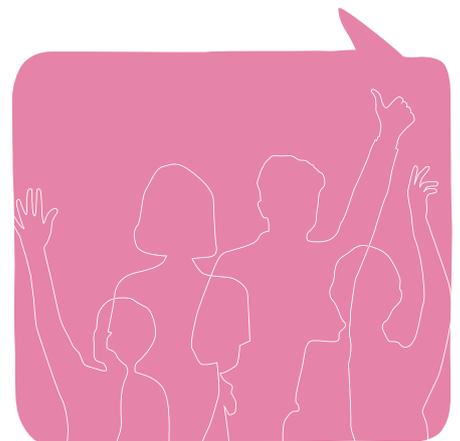
Executive Summary

July 2023



A survey of the views of parents and carers

of children and young people with special educational needs and/or disabilities (SEND)



Contents

3 Introduction	12 Childcare
3 Method and sample	13 Education
4 Identification and assessment of needs	14 Education Health and Care (EHC) plans
5 Social inclusion	15 Parental satisfaction with services
6 Impact on siblings	16 Transition
7 Impact on parental wellbeing	17 Communication and information
8 Training for parents	18 Complaints
9 Support from social care	18 What works?
10 Mental health and emotional wellbeing	19 Conclusions and next steps
11 Work and finances	20 Contact

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.

A full report can be viewed at: <https://sheffieldparentcarerforum.org.uk/about/publications/>

The survey was carried out by Sheffield Parent Carer Forum (SPCF) in March and April 2023 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 data gathered in 2014 and 2019.

Method and sample

Parents' views were sought through an online questionnaire, which was open for 5 weeks (between 6 March and 9 April 2023). The survey was advertised via SPCF's email list, SMS list, website and social media channels, and in Sheffield City Council's SEND email bulletin.

A total of **496 responses** were received. **85%** of respondents were members of Sheffield Parent Carer Forum. The response rate from SPCF members who were contacted via email or SMS was **20%**.

The questionnaire consisted of 72 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 15 minutes to complete the survey.

The sample covered the full range of children's impairment types, age groups (0-25 years), educational placements, parenting situations, and postcode

areas (including areas with high levels of economic deprivation). **38%** of respondents were in receipt of means-tested benefits and **21%** were non White British. **56%** of the children in the sample had an EHC plan and **18%** had a My Plan / Extended Support Plan.

496
responses
were received



Identification and assessment of needs

It is widely recognised that early identification and assessment of needs play a critical role in helping to ensure that children get the right support at the right time.

Many conditions can only be diagnosed by healthcare professionals. However, our survey indicates that the pandemic has worsened pre-existing capacity issues within children's community health services. Before the pandemic, families were already reporting long waiting times for diagnostic assessments; in 2023, the situation had deteriorated even further.

we found that children with a wide range of diagnoses often have very similar needs. Problems with social interaction affected **94%** of the children in our sample, **90%** struggled with sensory processing difficulties (e.g. oversensitivity to noise or smells, sensory-seeking behaviours), **81%** displayed challenging behaviours, **81%** were affected by anxiety and/or depression, **74%** had sleep issues, **69%** had issues with eating or drinking (including self-restricted diets) and **51%** had problems with continence or toileting. It was very common for children to have difficulties in more than one area.

Several respondents pointed out that a diagnosis is of limited use if there is little or no follow-up support:

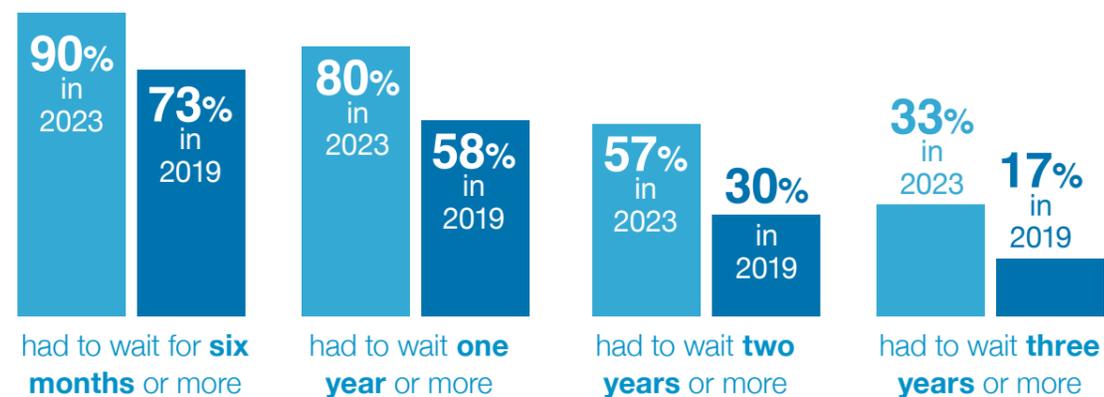
"My child doesn't have a diagnosis yet, we are still waiting, so we were told we couldn't access SNIPS"

"No help/support given. Wait times ridiculously long, you receive a piece of paper with a diagnosis and then you're just left to figure it out yourself. Online workshops offered but that's all. Absolute joke."

A diagnosis frequently serves as a passport to accessing support and services. While some services have attempted to address the waiting list crisis by waiving the diagnosis requirement and focusing on needs instead, numerous families still encounter barriers in accessing services due to the lack of a formal diagnosis.

Commissioning decisions also tend to be driven by diagnosis rates rather than needs. However,

Waiting times for assessments have surged:



Recommendations

Whilst we recognise that there has been a significant increase in referrals since the pandemic, key health services - particularly the Neurodisability service - should be prioritised to create additional capacity to work through the backlog and reduce waiting times for assessments.

Too many services still require a formal diagnosis as a precondition for accessing support. Sheffield City Council and NHS South Yorkshire Integrated Commissioning Board (NHS SY ICB) - Sheffield Place should carry out a review of eligibility criteria and replace diagnosis requirements with needs-based criteria, where possible.

We acknowledge that efforts have been made to mitigate the impact of the waiting list crisis by

contacting families of children on the waiting list for Neurodisability assessments, improving the information on the Sheffield Children's Hospital website and funding SPCF to run a Peer Support Service. These initiatives should be maintained and expanded to further improve pre- and post-diagnostic support for parents.

Commissioning must become more responsive to needs. Whilst efforts have been made to increase support for children with sleep problems and sensory processing issues, there are still significant gaps in provision around behaviour support, mental health issues, and problems with eating or drinking - particularly where these issues do not yet meet clinical thresholds for services like CAMHS.



Social inclusion

Families with children with SEND experience high levels of isolation.

Over **50%** of respondents said that caring for their child with SEND made it "difficult", "very difficult" or "impossible" to carry out everyday activities such as visiting friends or family, having people round, going out (e.g. for a meal or to the cinema), taking regular exercise, going out for the day, going on holiday or doing household chores.

18% said they felt isolated within their local community and within wider Sheffield. This constitutes an improvement on 2019, when **23%** felt isolated in their local community and **22%** felt isolated within wider Sheffield.

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 than in Integrated Resources and in mainstream schools. Compared to our 2019 survey, inclusion levels had increased for Integrated Resources (from **18%** to **26%**) and mainstream schools (from **23%** to **29%**), but fallen for special schools (from **63%** to **59%**).

72% of parents reported that their child with SEND was "sometimes" or "frequently" left out of social activities, e.g. not invited to parties.

34% of parents had given up work in order to cope with their caring responsibilities. This situation puts these

parents at a double disadvantage. Not only do they miss out on social interactions with co-workers, they also have fewer financial resources to participate in leisure activities.

Recommendations

Mainstream leisure providers (e.g. leisure centres, cinemas, theatres, restaurants, sports clubs) should invest in disability awareness training and work with disabled children, young people and their parents to identify and eliminate barriers to accessing services. This could include putting on disability-friendly events and/or providing additional support for families with disabled children.

Schools should apply learning from initiatives such as the Autism in Schools project to improve communication between staff and parents and help families of children with SEND feel more included within their school community.



Impact on siblings

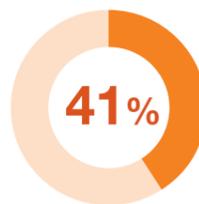
Most respondents said that having a disabled brother or sister had a negative impact on their other children. Only a small percentage (7%) reported no effect on siblings.

A lack of parental attention was identified as the biggest issue (62%), followed by missing out on family activities, restrictions on siblings' daily lives, and a negative impact on their mental health or emotional wellbeing (all reported by 41% of respondents). Additionally, 35% of respondents also said that siblings' sleep was disrupted.

"Most of the children have different needs and some do feel the other one gets more attention but the fact is they get overloaded at school and then also bring this home which doesn't help the atmosphere at home."



highlighted a lack of parental attention



identified a negative impact on siblings' mental health or emotional wellbeing



reported that siblings felt resentful towards their brother or sister with SEND

A significant proportion of respondents (35%) also recognised a positive effect, indicating that having a disabled sibling had made their other children more considerate, patient or understanding.

Having a sibling with SEND increases children's risk of isolation. Around a quarter of parents said that siblings were missing out on clubs and activities or could not have friends over. 29% of parents reported that siblings felt resentful towards their brother or sister with SEND.

Recommendations

Although there are some local organisations that provide support and activities for siblings of disabled children (such as Sheffield Young Carers or the SIBS project at the University of Sheffield), many families are not aware of this offer. Information about sibling support should be made more widely available, e.g. via the Local

Offer, education providers, social care services and healthcare professionals.

Short break services provide parents with a valuable opportunity to spend quality time with their non-disabled children. These services should be better publicised and easier to access (see page 9).



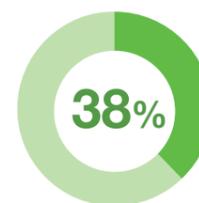
Impact on parental wellbeing

94% of respondents reported that caring had affected their wellbeing.

80% said that caring had impacted their emotional wellbeing. 71% of respondents reported experiencing adverse effects on their mental health, while another 71% said that it had affected their sleep. 56% also reported a negative impact on their physical health and their relationships.

Looking at our previous surveys, we observed a consistent decline in parents' mental health. In 2014, 49% of parents reported that caring had a negative impact on their mental health, which increased to 64% in 2019, and further rose to 71% in 2023. This trend is likely to reflect the impact of both the pandemic and austerity measures.

Responses suggest that around a third of parents are at breaking point:



said that they were "struggling" or "not coping" with their caring responsibilities.



said that they often neglected themselves.



stated that they had never had a day or an evening off from caring.



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. 30% of parents had a disability or long-term illness themselves, 39% had more than one child with SEND, 17% also provided care for an adult over the age of 25, and 22% were lone parents.

Several parents told us that it wasn't their child's disability which was impacting on their mental health, but rather the fight to secure services for them.

Recommendations

Sheffield City Council should promote short break services more widely to parent carers, using a range of communication methods.

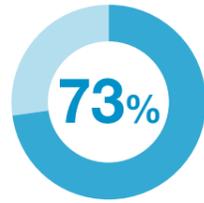
Sheffield City Council should review the eligibility criteria for short break services. Given the long waiting times for Neurodisability assessments, the requirement for children to have a formal diagnosis should be dropped.

Sheffield City Council should ensure that the needs of parent carers are considered through a distinct carer's assessment which considers their need to work and to access education, training and leisure activities.

NHS SY ICB (Sheffield Place) should commission specialist counselling for parent carers.



Training for parents



of respondents said that they wanted training to help them better support their child with SEND.

Their top priorities were:

- Supporting their child's emotional wellbeing/mental health
- Managing challenging behaviour
- Teaching their child life skills
- Helping their child with demand avoidance / PDA
- Helping their child with sensory issues
- Helping their child be safe in traffic
- Supporting communication / speech and language development
- Understanding their child's disability
- Teaching their child about puberty / sex and relationships
- Helping their child with eating / feeding issues



of respondents said they wanted training to help them cope better with their caring situation.

Their top priorities were:

- Understanding their rights as carers
- Managing their child's transition to adulthood
- Getting support for their child in school/college
- Managing their own wellbeing/stress
- Understanding disability benefits
- Supporting the siblings of their child with SEND
- Making a will and setting up a trust
- Getting support from social care
- Getting support from health services
- Looking after their relationships (e.g. with partner, other children)
- Managing direct payments and employing PAs

There was mixed feedback about the specialist parenting courses currently on offer. Around half of respondents said that the courses run by the Sheffield Parenting Hub and the Ryegate workshops (both live and recorded) were "not useful at all" or only "slightly useful". The Managing ADHD course run by Family

Action received more positive feedback, with **40%** stating that they found it "very" or "extremely" useful.

Several respondents stated that they were unaware of any specialist parenting courses.

Recommendations

There is a disconnect between the training currently on offer, and the training that parents say they want. A review should be carried out to ensure that the training offer meets parents' needs.

Training should be more widely publicised, particularly to parents of children waiting for an assessment, and at the point of diagnosis.



Support from social care

34% of survey respondents were receiving a social care service, **66%** were not.

The main reasons for not accessing support from social care were a lack of information about these services (**41%**) and the assumption that their child would not be eligible (**34%**). **17%** said they didn't have the time or energy to apply.

We asked those parents who were in receipt of social care support whether they thought that their current package was meeting their needs. **32%** said that it wasn't. Whilst still high, this signifies a notable improvement compared to 2019, when this figure stood at **55%**. However, several parents said that they were unable to use the services they had been assessed as needing.

Parental satisfaction with social care services varied widely between services. Whilst SNIPS and the Short Break Grant received predominantly positive ratings, other services were viewed less favourably. Of particular concern are MAST intervention workers, which were rated as "Poor" or "Very poor" by **45%** of respondents, and the Transitions/PAT team, which received such ratings from **63%** of respondents.

The prolonged closures of several respite care homes for children had a clear impact on parental satisfaction with overnight respite. There was a sharp decline in satisfaction with this service compared to 2019, and a steep increase in the number of parents who rated service capacity as "too little".

"We only currently get direct payments, but we are unable to use the money as we are unable to recruit/retain a PA [Personal Assistant] and we are unable to use the funds for alternative services, such as help with the added household demands."

"We don't currently get any support and I'm not sure how we would be assessed as needing support. It feels like you have to be in a crisis before you can access some of this stuff. We are not in a crisis but we do get very tired and some respite would be nice, even if just a club."

Recommendations

There needs to be a sustained effort to attract more people into PA roles, and to support families with the recruitment, training and retention of PAs.

Families should be enabled and supported to use Direct Payments more creatively and flexibly, i.e. not just to employ PAs.

Sheffield City Council should carry out a review of overnight respite to ensure that there is sufficient capacity for emergency placements, to avoid any closures of children's respite care homes in the future.

Sheffield City Council should carry out a review of SNIPS clubs to ensure that these are accessible to all eligible children, with more choice. The diagnosis requirement for SNIPS clubs should be dropped.

SNIPS should work with a wider range of mainstream clubs to make them more accessible for disabled children.

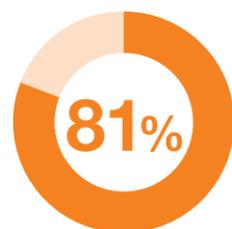
The short breaks offer should be publicised more proactively and in a way that is easier for parents to understand.



Mental health and emotional wellbeing

Survey responses highlight a growing and often unmet need for mental health support.

Within our sample, **16%** of the children had a primary need related to Social, Emotional and Mental Health Difficulties. However, this figure does not adequately reflect the high incidence of comorbid mental health difficulties among children with other diagnoses. **81%** of the parents in our sample said that their child with SEND was affected by anxiety and/or depression, with **36%** of children reported to be “severely” affected.



81% of the parents in our sample said that their child with SEND was affected by anxiety and/or depression

78% of parents said that their child was getting too little or no input from CAMHS. When asked whether there were any services that their child needed but wasn't currently getting, mental health support emerged as the top priority.

Parental awareness of Healthy Minds was low, with **75%** of respondents stating they did not know whether their child's school was involved in this project. This is despite the fact that Healthy Minds was launched in 2017 and is reported to have reached over **80%** of Sheffield's mainstream schools.

When we asked parents about their training needs in relation to supporting their child with SEND, “supporting my child's emotional wellbeing or mental health” was the most requested topic (selected by **52%** of respondents). We are not aware of any relevant training that is open to all parents of children with SEND.

Compared to our previous surveys, there was a sustained increase in the percentage of parents who reported that caring for a child with SEND was having a negative impact on their own mental health. In 2014, **49%** of parents reported such an impact, which increased to **64%** in 2019, and further rose to **71%** in 2023.

41% also said that their other children's mental health and/or emotional wellbeing was affected by having a sibling with SEND.



78% of parents said that their child was getting too little or no input from CAMHS

Recommendations

NHS SY ICB (Sheffield Place) should develop an adequate mental health support offer for children and young people with SEND, as well as their parents and siblings – particularly for those who do not meet thresholds for clinical services like CAMHS.

The existing offer, though limited, needs to be better publicised to families.

Schools should make sure that both pupils and parents are aware of any mental health support they offer, e.g. through assemblies, newsletters, their websites and SEND information reports.

This applies to all schools, but particularly Healthy Minds schools.

Services should work in a multi-agency way in relation to mental health and SEND. This could be through the Children and Young People Delivery Group and the Mental Health and Learning Disabilities, Dementia and Autism Board.

Sheffield City Council and/or NHS SY ICB (Sheffield Place) should offer training to parents on how to support the emotional wellbeing and mental health of their child with SEND.



Work and finances

Caring for a child with SEND can have a detrimental impact on parents' ability to work.

Only **20%** of the parents in our sample were managing to work full time, and **41%** were working part-time.

85% of parents said that caring had affected their ability to work. Of these parents, **34%** had given up work to cope with their caring responsibilities, **43%** had reduced their hours and **25%** had taken a less challenging job.

Responses emphasized that issues with their child's education can significantly affect parents' ability to work. Examples include frequent unscheduled time off school (e.g. due to exclusions), and children being put onto part-time timetables or left without a suitable school placement for long periods of time. These issues can make it impossible for parents to maintain regular employment.

67% of parents said that their family was worse off as a result of caring for their child with SEND. This is more than in 2019, when this figure stood at **58%**. According to research by the Childhood Trust, families with disabled children have been disproportionately affected by the cost-of-living crisis.

At the same time, our surveys revealed a consistent decrease in the percentage of parents who reported receiving means-tested benefits. In 2014, **57%** of parents were in receipt of such benefits, which declined to **45%** in 2019, and further decreased to **38%** in 2023.

35% of respondents to our 2023 survey said they wanted training to help them better understand disability benefits.

We frequently receive enquiries from parents looking for help with completing benefit application forms. The only service currently offering this is Citizen's Advice Sheffield, but there are long waiting lists.

My daughter is not currently in school due to school not being able to meet her need, and [despite] them stating this she was placed there anyway. Despite trying reduced timetables, reduced demand etc. my daughter had a breakdown moment on her way to school in February and hasn't been able to attend since. She is struggling to leave the house at all at the moment! Her AP [Alternative Provision] have been amazing and are giving her a reason to still engage in the outside world. I had to leave my role when this happened and I had already reduced hours due to the reduced timetable.

"I need to work flexible hours to cover my caring responsibilities but that means I work till late at night after putting children to bed. This is very challenging on a long term."

Recommendations

Sheffield City Council should commission a range of services to provide benefits information and advice to parent carers and support them with form-filling.

Sheffield City Council should extend the Holiday Activities and Food (HAF) programme to include children with EHCPs who are not in receipt of means-tested free school meals and offer more SEND-specific activities.

Sheffield City Council should commission sufficient special school places and increase both the level of challenge and the support provided to schools in relation to part-time timetables and exclusions of pupils with SEND.

Sheffield City Council should widen the offer for young people with SEND who are leaving education, particularly for those who do not meet the threshold for support from adult social care.



Childcare

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

Whilst this combined figure was the same as in our 2019 survey, the percentage of parents who said that finding childcare was “impossible” had increased from **24%** in 2019 to **33%** in 2023.

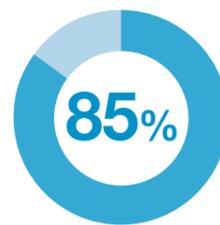
85% of parents said that caring had affected their ability to work. **36%** of these parents said they had been unable to find suitable childcare for their child with SEND, and **19%** said they couldn't afford it.

“Just want to sing the praises of B Nursery School! I have found the EHCP process very difficult and we have complained about SENDSARS. However, the SENCO at B has been amazing. My son has come on so much since going to this nursery and they are constantly adapting plans and strategies in nursery to meet his needs and help him develop. All the staff are really friendly and helpful and it is so good for us as a family.”

“Getting way less than is entitled to at nursery. Reduced hours/days to less than started on, very basic and part time. Feels so tiring and hardly worth the effort to get them there.”

Relatively few families in the sample used formal childcare for their child with SEND, with **41%** relying on family members, friends and neighbours instead. **20%** were employing a personal assistant, **14%** accessed mainstream after-school clubs, and **11%** used childminders.

Local authorities have a legal responsibility to ensure that there is sufficient childcare provision for children with SEND up to the age of 18 years, and to evaluate this through an annual Childcare Sufficiency Assessment.



85% of parents said that caring had affected their ability to work.

Recommendations

Sheffield City Council should better publicise the Disability Access Fund (which provides inclusion funding to childcare providers for eligible 3- and 4-year-olds), to both childcare providers and parents. Take-up of this fund is low, which may be due to the fact that children must be in receipt of Disability Living Allowance to qualify (see also page 11).

Sheffield City Council should use the annual Childcare Sufficiency Assessment to identify gaps in childcare

provision for children and young people with SEND, and work with parents and providers to develop strategies to plug those gaps.

Sheffield is one of 16 local authorities chosen to pilot the Government's plans to provide wraparound childcare for primary school aged children. It is essential that this work considers children with SEND, and particularly those who attend special schools, from the outset.



Education

44% of parents said that their child's educational provision met their needs, **42%** said that it did not, and **15%** didn't know.

Satisfaction levels varied significantly between school types, with special schools receiving the highest ratings, Integrated Resources falling in the middle, and mainstream schools receiving the lowest ratings.

Looking at ratings over time, mainstream settings and Integrated Resources appear to have improved slightly since 2019, although they are still below levels recorded in 2014. Special school ratings, on the other hand, are showing a gradual decline, albeit from a very high baseline. This may be due to the fact that many of our special schools are overcrowded.

Where parents reported that their child's educational setting did not meet their needs, they highlighted several key issues. The most significant concerns mentioned were a lack of staff training and understanding regarding their child's specific needs, inadequate support for their child's anxiety or mental health issues, and concerns about the quality of communication. Moreover, more than half of these parents rated the amount and quality of support, as well as the provision of reasonable adjustments and adaptations to the environment, as “poor.”

Several parents said that their child's current placement was wrong and that a more specialist placement was needed.

“The school try hard and are a good school but are unsuitable for my child. They also say they cannot meet need.”

Parents who felt that their child's educational provision met their needs:

72% of parents of children in special schools

48% of parents of children in IRs

30% of parents of children in mainstream schools

Part-time timetables were not uncommon among the children in our survey. We discovered that **14%** of mainstream pupils and **11%** of special school pupils aged 5-15 years did not attend school for five days per week. It is worth noting that only **11%** of the children on part-time timetables were attending an alternative provision.

Bullying affected a large number of children, particularly in mainstream schools. **53%** of respondents said that their child had “sometimes” or “frequently” experienced bullying by other children (compared to **63%** in 2019).

Recommendations

Sheffield City Council should continue to fund initiatives that can evidence a positive impact on enhancing inclusion in mainstream schools, such as the Autism in Schools project and the Inclusion Taskforce.

It should be compulsory for all school staff to attend SEND training as part of their continuing professional development.

Sheffield City Council should develop a robust sufficiency plan to ensure there are enough special

school places / specialist provision over the next five years, setting out the steps needed to achieve this.

Schools should proactively review their policies and be open to making reasonable adjustments to accommodate the needs of children and young people with SEND. This is in line with the Sheffield All-Age Autism Strategy, where one of the priorities is to “Ensure all schools provide neurodiverse accessible environments, with commitment and improved awareness and acceptance from all school leaders”.



Education Health and Care (EHC) plans

Parental satisfaction with EHC needs assessments has improved.

In 2019, **77%** of parents rated the process as “difficult” or “very difficult”. In 2023, this number decreased to **59%** - which, although improved, is still unacceptably high. (It should be noted that many of the 2019 respondents may have answered the question in relation to statement-to-EHCP transfers - which were often rushed through at the expense of quality - rather than new EHC plans.)

An EHC plan is a formal legal document which places a statutory duty on the local authority and the health service to arrange the special educational and healthcare provision described in it. However, only **16%** of parents of children with EHC plans reported that their child was getting all of the provision described in their plan.

Parental feedback about the SEND Statutory Assessment and Review Service (SENDSARS) had also improved, albeit from a very low baseline:

71% in 2019

49% in 2023



Respondents who rated SENDSARS “poor” or “very poor”

89% in 2019

67% in 2023



Respondents who said they had received too little input from SENDSARS

“Complete inability to put the EHCP measures in place due to poor SENCo and headteacher. My child is distressed and left to cry alone till friends intervene and support. They are ignoring other children with SEN needs too.”

Annual reviews of EHC plans

Survey responses indicate that compliance with statutory requirements in relation to annual reviews has improved since 2019. However, significant challenges still persist in 2023:

- **29%** of parents said that their child’s EHC plan had not been reviewed in the past 12 months.
- **59%** had not received reports at least two weeks before the review meeting.
- **48%** had not received a letter regarding the outcome of the review within four weeks after the meeting.

Parents and the local authority often disagree about whether an EHC plan should be updated. **54%** of respondents said that they had requested changes to their child’s EHC plan which had not been made.

Recommendations

We are pleased to see some improvements with regard to EHC needs assessments and SENDSARS, but there is clearly still a long way to go. At the time of writing, an independent review of SEND services, commissioned by the local authority, was taking place. We look forward to seeing the recommendations from this review, and expect that they will be implemented in full.

Annual review paperwork should include a question to establish whether the provision described in sections F and G is being made. SENDSARS should follow up on any reports of non-implementation with relevant providers.

SENDSARS should develop a document setting out when an EHC plan will / will not be amended. This information should be available on the Local Offer website.



Parental satisfaction with services

Education support services

We saw a significant improvement in quality ratings for Educational Psychology, the Autism and Social Communication Team, and outreach from Becton and special schools compared to 2019. However, these ratings still fell below the levels recorded in 2014. Quality ratings for the Hearing and Vision Support Services remained unchanged.

Capacity ratings for education support services have also improved since 2019 and are now similar to the levels observed in 2014, except for the Vision Support Service, which appears to be facing increasing strain. Nevertheless, significant capacity issues persist in many services. For example, **72%** of respondents said that their child received too little or no input from the Autism and Social Communication Team, and **75%** said this about Educational Psychology.

Social care

We observed a significant decline in both quality and quantity ratings for overnight respite compared to 2019. This is probably due to the recent closures of three children’s respite care homes to accommodate emergency placements.

Quality ratings remained high for SNIPS clubs and the Short Break Grant. As in 2019, ratings were significantly lower for the Children with Disabilities Team, MAST Intervention Workers, adult social care, and the Transitions / Preparing for Adulthood Team.

Capacity ratings for most of these services declined compared to 2019. The services with the lowest ratings were adult social care, rated as providing too little or no input by **81%** of respondents, followed by the

Respondents who said their child was getting too little or no input:

72% from Autism & Social Communication Team

75% from Educational Psychology

75% from Ryegate Neurodisability Service

77% from Transitions / PAT team

78% from CAMHS

80% from Speech and Language Therapy

81% from Adult Social Care

Transitions / Preparing for Adulthood Team (**77%**), and MAST Intervention Workers (**70%**). Only the Children with Disabilities Team showed a slight improvement in both quality and quantity ratings.

Health services

Quality ratings for most of the specialist and universal health services we looked at had deteriorated compared to 2019. Only CAMHS and Health Visitors showed an improvement against 2019, when they were amongst the lowest-rated services.

Capacity ratings for most specialist and universal health services also experienced a decline. The services that ranked poorly in 2019 continued to be the worst performers in 2023. For instance, **80%** of respondents reported that their child received too little or no input from Speech and Language Therapy, **78%** said the same for CAMHS, and **75%** expressed this regarding the Ryegate Neurodisability Service. In addition, school nursing and adult hospitals are now among the worst-performing services, with **73%** of respondents stating that their child received too little or no input from these services.

Missing services

We asked parents if there were any services that their child needed but was not currently getting, and **74%** said “yes”. The most commonly reported missing services were mental health support, speech and language therapy, occupational therapy, ASD and ADHD assessments, social care support, educational psychology, transition support, overnight respite and social activities/clubs.

Recommendations

Sheffield City Council and NHS SY ICB (Sheffield Place) should review the funding, caseloads and service models of specialist SEND support services, to establish whether higher-performing services share specific characteristics which could be adopted by other services.

Sheffield City Council and NHS SY ICB (Sheffield Place) should increase the capacity of services that are currently unable to meet demand.

Sheffield City Council and NHS SY ICB (Sheffield Place) should publish clear information about eligibility criteria, access routes, target response times, service standards and complaints procedures for all specialist services on the local offer.



Transitions

Transition was one of the seven areas of weakness identified during the local area SEND inspection conducted in November 2018.

When a revisit was carried out in February 2022, Sheffield was found to have made insufficient progress in addressing this issue. As a result, the local area was directed to produce an Accelerated Progress Plan to address the identified shortcomings and improve transition support for children and young people with SEND.

Transition to secondary school

63% of respondents found the transition from primary to secondary school "difficult" or "very difficult", which represents an increase from 53% in our 2019 survey. This may be due to the impact of the pandemic, which limited the transition activities (such as open days, familiarisation visits) that schools were able to carry out.

Transition to adulthood

A majority of parents continue to report difficulties with their child's transition to post-16/19 education, adult social care and adult health services.

Compared to our 2019 survey, the percentage of parents who rated the transition process "difficult" or "very difficult" had decreased by 8% for education, increased by 7% for health services, and remained virtually unchanged for social care.

A striking 75% of respondents reported receiving no helpful information, advice or support from services

"(...) Despite there being a role created [to support transition] it is meaningless unless there are providers / services available for them to signpost to. It is an on the sticking plaster move by the LA for the current situation of lack of transition in LA which should have been available for the last ten years at least."

regarding their child's transition. This percentage was significantly higher than the 55% recorded in 2019.

We asked those parents who had received help with transition to rate the service that provided it. Only school/college, SNIPS, SENDIAS and health professionals received a "good" or "very good" rating from at least one third of respondents. On the other hand, social workers, MAST, DWP/Jobcentre Plus and the local offer website were rated as "poor" or "very poor" by over 50% of respondents.

Recommendations

Transition must remain a top priority when the Accelerated Progress Plan ends. To maintain the momentum gained, a strategic role should be created to oversee and drive forward the Preparation for Adulthood agenda across education, health and social care.

We welcome the creation of a dedicated social care transitions team. However, the fact that 63% of respondents rated this team "poor" or "very poor" is concerning. Improving the service provided (e.g. through easier access, improved processes, more training, better leadership) could have an immediate impact.

Ensuring a good transition to adult services is not just about the process of transition but also about the quality and range of services that young people are able to access. Work on expanding the range

of available options has only just begun and needs to be accelerated further. It is vital that commissioners are aware of, and responsive to, the interests and aspirations of the young people coming through the system.

We are pleased to have co-produced a new transitions guide for parents with the local authority. This guide must now be promoted widely, e.g. via the Local Offer website, SEND Facebook group, SEND bulletins, health communication channels and SENCO briefings. All settings and services should refer to the transitions guide as their go-to resource for helping parents navigate the transition process.

Young people with health needs should have a detailed health transition plan put in place, well in advance of moving from children's to adult services.



Communication and information

Communication

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 individual providers, overall ratings show that education settings lead the way:

- 48% of parents said that the communication they had with their child's nursery, school or college was "good" or "very good"; 36% thought this about health services, and 18% about social care services. All of these services showed a slight improvement compared to 2019.
- On the other hand, 30% of parents rated the communication they had with their child's education provider as "poor" or "very poor", 32% thought this about health services, and 57% about social care services.

Information

Access to timely and accurate information can have a significant impact on parents' ability to cope. Without this information, families may miss out on early support and often only come to the attention of services when problems have become entrenched.

To address this, the local offer website was launched in 2014. It aims to provide a one-stop shop for information about support and services for children and young people with SEND.

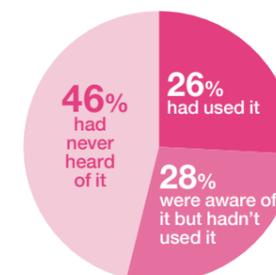
However, our survey revealed that website usage among parent carers remains low, with only 26% of

respondents reporting that they had accessed it. Among those who did use the website, most had discovered it through internet searches, word of mouth, or referrals from professionals. These findings highlight the need for further efforts to promote the website.

The percentage of respondents who thought the website was "good" or "very good" had increased from 16% in 2019 to 31% in 2023. A higher percentage of users reported that they had been able to find what they were looking for and that the information was easy to find, clear and up to date. These positive changes may be attributed to the development and improvement work carried out on the local offer website by Sheffield Parent Carer Forum in recent years, as well as the creation of a dedicated Local Offer officer role in 2022, and the recent migration to a more user-friendly platform.

Sheffield SENDIAS (SEN Information Advice and Support) plays a crucial role as an advisory service for parents of children and young people with SEND. 63% of respondents rated this service as "good" or "very good". However, 50% said that there wasn't enough of it.

The local offer website



Recommendations

The fact that 57% of respondents rated communication with social care services as "poor" or "very poor" gives cause for concern. There has been little improvement since 2019, when this figure stood at 60%. The issue should be addressed by co-producing and implementing a set of communication standards for social care services.

Whilst the improved feedback on the Local Offer website is encouraging, there is still a long way to go to turn the site into the central information point it was intended to be. A marketing campaign is needed to raise awareness amongst parents and professionals.

Establishing a continuous feedback loop with parents is vital; this includes the feedback gathered by organisations such as SPCF and SSENDIAS and posts

in the new SEND Facebook group. All this feedback should be used to fill gaps in information and ensure that the Local Offer is relevant and up to date.

SSENDIAS is clearly valued by parents, and it is vital this service is adequately funded to ensure it can meet demand.

Family Centres have been transformed into Family Hubs and should be the place to access information in local communities. However, these hubs need to build upon the existing services that are in place to be able to truly support families from pregnancy through a child's early years until they reach adulthood. This includes working closely with community youth services and clearly communicating the offer to families.



Complaints

There was a decrease in the percentage of parents who had lodged complaints about services. In 2023, **33%** of respondents reported making complaints, compared to **44%** in 2019. These complaints encompassed various forms, including 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 to go down the formal or legal route. This may be due to the fact that complaints procedures in education are better publicised than in health and social care.

48% of parents said that they had found it "difficult" or "very difficult" to make a complaint.

The success rate of complaints was low, with only **15%** of parents reporting that their complaint had fully resolved the issue at hand. For **36%** of parents, the complaint led to a

partial resolution, while for **39%**, it did not bring about any satisfactory resolution.

Several parents expressed a lack of faith in the complaints process, as their concerns were investigated by the same staff whom the complaints were about.

Recommendations

Services should publish clear and easily accessible complaints procedures on their websites and signpost to this information from any relevant correspondence.

Complaints should be investigated by an impartial and independent individual or service.



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 previous surveys, back in 2014 and 2019. This enabled us to assess how parental satisfaction with local services has changed over the years.

It should be noted that this is a comparison of surveys conducted before and after a global pandemic and the cost-of-living crisis that followed it. These factors will undoubtedly have influenced responses.

Whilst it was encouraging to see improved feedback in relation to some services, these enhancements were often modest and frequently stemmed from a low starting point. More work is needed to ensure that improvements continue and become embedded.

What we will do

We will present our findings and recommendations to strategic leads in Sheffield City Council and NHS South

Yorkshire Integrated Care Board (Sheffield Place) as well as relevant providers of education, health and social care services. We are committed to working with them to address the key issues identified in this report.

In particular, we will keep highlighting parental feedback in relation to the transition to adulthood, in order to maintain the momentum gained through the Accelerated Progress Plan and ensure that recent activities have a positive impact on the ground.

We will also submit this report as part of our involvement in the next local area SEND inspection, which is due imminently.

Last but not least, we will use the findings from this survey to develop our own service offer. For example, we will offer information sessions in response to the training needs identified by parents through this survey.

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



What works?

When parents discuss good practice, they often highlight specific individuals rather than systems or processes. Many parents shared stories about

dedicated staff members who had gone above and beyond to support their child.

When describing the positive contributions made by these individuals, parents repeatedly mentioned a number of key traits:

- Communicates thoroughly and regularly
- Proactive
- Supportive
- Listens without judgement
- Values parental expertise
- Honest and clear
- Caring
- Goes above and beyond
- Does what they say they will
- Consistent approach
- Involves children and parents
- Willing to adapt to the child, review strategies and make adjustments
- Accessible
- Knowledgeable
- Involves other services

Many respondents also praised specific schools and services, including a range of NHS and local authority

services, voluntary sector organisations and parent support groups.





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The full report

To access the full version of this report, please go to:
<https://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 over 2,400 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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