

SEND Futures Experiences

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Healthwatch Richmond
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We are committed to quality and the continuing improvement of our work. We perform an in-depth audit at least every 3 years to support this.

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Glossary

AfC: Achieving for Children

ASC: Autism Spectrum Condition

CAMHS: Children and Adolescent Mental Health Service. CAMHS assesses and treats children and young people with emotional, behavioural or mental health difficulties.

CQC: Care Quality Commission

EHCP: Education Health and Care Plan. This is a legal document created by the Local Authority which describes a child's or young person's special educational needs, the support they need, and the outcomes they would like to achieve.

IEP: Individual Education Plan

LA: Local Authority

MDT: Multidisciplinary Team

NDT: Neurodevelopmental Team

OT: Occupational Therapist

SALT: Speech and Language Therapist

SENCO: SEN co-ordinator

SEND: Special Educational Needs and Disabilities

Introduction

This report presents responses from 103 parent carers regarding their experiences of the support and services provided to children with SEND in Richmond. No exclusionary time frame was applied to this data and so it encompasses parent carers' total experience up until Summer 2023. In addition, the report includes narratives from 21 professionals about their experience of working and supporting children with SEND in the borough. The report focuses on six areas:

- SEND identification and assessment,
- Parent carer involvement in decision making about their child,
- Perception of help and support received,
- Preparedness for changes in education and life,
- Involvement wider community activities,
- Quality of support information.

While parent carers reported positive experiences with SEND services, particularly praising educational services, the report highlights the range of challenges they face. These include delays in assessments and diagnoses, limited support services, lack of clarity in navigating the system, and struggles during transitions between educational stages and adulthood. Parent carers underlined their reliance on personal networks and online communities to navigate the complex SEND system and access relevant information. This report emphasises the importance of individualised support, effective communication, collaboration among professionals, and inclusive practices within schools and communities.

In addition, parent carers stress the significance of early intervention, proper training and awareness among professionals, and the need for easily accessible information and resources. Positive experiences and successful outcomes were attributed to supportive school environments, personalised plans, and collaboration between schools, local authorities, and families.

The responses in the report underscore the importance of recognising and valuing individuals with SEND as unique individuals with distinct needs. There is a call for

increased awareness, inclusivity, and celebration of disabilities within the community.

Overall, the report reflects the diversity of experiences and perspectives of parent carers dealing with the challenges of supporting children with SEND. It emphasises the need for improved communication, collaboration, access to information, and resources to ensure that individuals with SEND can thrive and lead fulfilling lives.

Background

The SEND Futures Plan stands as Richmond's strategic blueprint, aimed at enhancing the quality of life and opportunities for children and young adults, aged 0 to 25 years, who possess special educational needs and disabilities (SEND). This comprehensive initiative encompasses the realms of education, health, and care, with a pivotal focus on ushering in improvements across these domains. At its core, this plan not only endeavours to advance the well-being of the target demographic but also seeks to ensure the sustained financial viability of a system that has faced substantial strain over recent years.

Championing a collaborative approach, the SEND Futures Plan embraces multi-agency coordination, spearheaded by prominent statutory entities like the Local Authority and the Integrated Care Board. This collaborative fabric also extends to include partners from diverse sectors, including the voluntary domain. Formally adopted by Richmond Council during the summer of 2019, the plan underwent its most recent revision in the summer of 2021.

As of January 2023, Richmond was responsible for 1,706 Education Health & Care Plans (EHCPs). The numbers of individuals in each age group are:

- 0 - 4 years old: 41
- 5 - 10 years old: 548
- 11 - 15 years old: 678
- 16+ years old: 439

Richmond also caters to the needs of 2,791 students who receive support but do not have EHCPs. This figure accounts for 9.7% of the overall student populace within the borough.

In 2014, Richmond created a community interest company, Achieving for Children (AfC) which provides education and children's social care services on behalf of the Local Authority (LA). Richmond Council, in collaboration with the Integrated Care Board and Achieving for Children (AfC), asked Healthwatch Richmond to gather information about SEND services in the borough from the experience of parent carers, professionals and service users.

The aim of this work was to understand the efficacy of existing services, pinpointing strengths and areas for improvement that could meaningfully improve outcomes for 0–25 year olds with SEND. The primary objectives were to gain insights into the ways in which the needs of children with SEND were currently being addressed and to identify areas that could be modified to enhance the support provided. Moreover, we wanted to examine the experiences of utilising SEND services from the perspective of individuals with caregiving responsibilities.

While this work was being completed, Ofsted and Care Quality Commission (CQC) announced that an inspection would take place in October 2023. Inspection comments are embedded within this report where relevant. The inspection concluded that:

“The local area partnership’s special educational needs and/or disability (SEND) arrangements typically lead to positive experiences and outcomes for children and young people with SEND.”

It listed three areas for improvement:

1. Leaders at NHS South West London ICB should ensure that there are robust oversight and improvement plans to reduce the lengthy waits for children and young people waiting for an autism or ADHD diagnosis;
2. Leaders in the local partnership should ensure that all expectant parents are able to access an antenatal contact from a health visitor; and
3. The local area partnership should improve the quality of information in EHC plans so they reflect the current needs and outcomes for children and young people with SEND.

Methodology

Data from parent carers was collected through an online survey consisting of structured and open-ended questions. We created three surveys: Parent Carer Survey, Young Persons Survey and a Professionals Survey. The surveys were created in partnership with AfC Richmond and parent carers. The surveys were designed to capture information related to six key areas:

- SEND identification and assessment,
- Parent carer involvement in decision making about their child,
- Perception of help and support received,
- Preparedness for changes in education and life,
- Involvement in wider community activities,
- Quality of support information.

Inclusion criteria required participants to be parent carers of children with SEND in Richmond, a young person using SEND services in Richmond, or a professional working with children with SEND in the Richmond borough.

Together with our partners, we promoted the survey through various outreach channels, including local support groups, educational institutions, social media and online channels and communities.

Narratives from the survey were analysed using thematic analysis. Coding was used to identify recurring themes and patterns within the data. These themes were then organised into meaningful categories to gain a deeper understanding of the experiences related to children with SEND.

Limitations

The sample, at 2.3% of the parent carer population, may not fully represent the entire population of parent carers and professionals in Richmond. Additionally, the study relied on self-reported data, which may be subject to bias.

We received insufficient responses from the young people's survey. In parallel to our work, our partners AfC Richmond conducted focus groups with young people who

are users of SEND services. AfC's separate report should be read alongside our findings to ensure that a full understanding is achieved.

As this work aims to inform improvements rather than to form judgements of the current state of provision, we included as many experiences as possible. No attempt was made to identify whether responses relate to current or historic experiences. The findings of this report therefore cannot inform judgements about the current state of provision which may or may not reflect these findings.

Recommendations

We recognise that these findings do not exist in isolation but relate to changes already underway with SEND services and the forthcoming Action Plan following the Ofsted/CQC inspection. They also reflect experiences from people who used services before and while changes were being made and may not fully reflect any recent improvements. We therefore recommend that Achieving for Children consider the following within its Action Plan:

1. **Promote Effective Communication and Collaboration:** Foster an environment that encourages and facilitates efficient communication and collaboration among professionals, service providers, and parent carers.
2. **Facilitate Accessible Information and Resources:** Make information and resources easily accessible to parent carers, professionals, and service users, empowering them with the knowledge and tools required to navigate the system effectively.
3. **Tailor Support to Individual Needs:** Develop programmes that tailor support for children with SEND, aligning services and interventions with their specific requirements.
4. **Enhance Transition Support:** Improve the transition process for individuals with SEND as they progress between educational stages and transition into adulthood. This could perhaps be achieved through improved clarity of communication, collaboration, and the creation of tailored support plans.
5. **Promote Early Intervention:** Encourage early intervention through training and awareness programs for professionals working with children with SEND. This proactive approach may help in early identification and resolution of issues.
6. **Champion Unique Abilities:** Support the cultivation of a culture that celebrates the distinct talents and abilities of individuals with SEND within the community. This celebration promotes inclusivity, understanding, and acceptance.
7. **Engage the Community:** Involve the community in discussions and initiatives aimed at creating a more inclusive and supportive environment for individuals

with SEND. This engagement may foster a sense of collective responsibility and commitment to positive change.

Results

103 parent carers and 21 professionals provided responses detailing their experiences of SEND services in Richmond.

Quantitative responses were generally mixed. It should be noted that quantitative ratings express an overall agreement or disagreement with a statement. This is not equivalent to, and should not be considered to be, a positive or negative rating of these aspects of experience.

The qualitative responses in this report skew towards negative experiences. While positive responses were provided, and we have taken steps to ensure that they are reflected fully in this report, many were equivocal in nature, for example:

“We have an annual review every year in which we meet with school and work together with the professionals reports. A few times, it was suggested that OT intervention could be removed but we insisted that our [child] needed it. Luckily, our voice was heard and our [child] still has OT support which helps him/her to make progress. It would be much better for parents if we didn’t have to keep fighting for our children to have the support they need.”

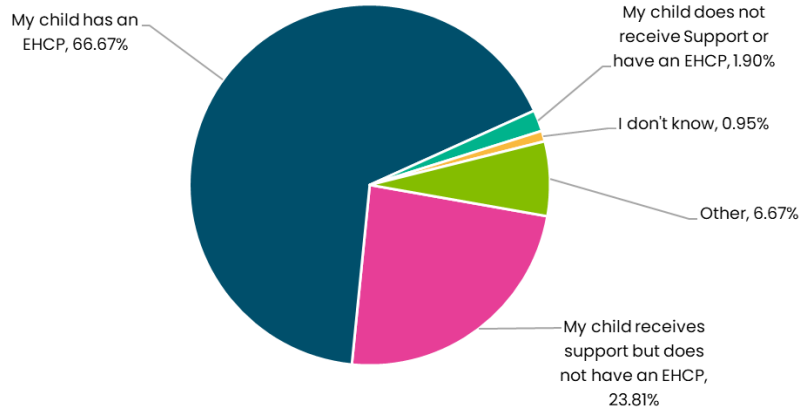
“I was very much involved but, and this is my perception, not always listened to. School listened to me but I don’t believe that any of my [child’s] case workers actually knew very much about him/her or his/her needs and were very quick to recommend options that were in no way suitable.”

“My child’s physical needs were assessed in a timely way, but his emotional, sensory and mental health needs have not been adequately reflected in his EHCP and it is very challenging trying to get them to be properly recognised and supported”

The following pages thematically set out the responses to the survey. Responses from professional participants are clearly marked under separate headings.

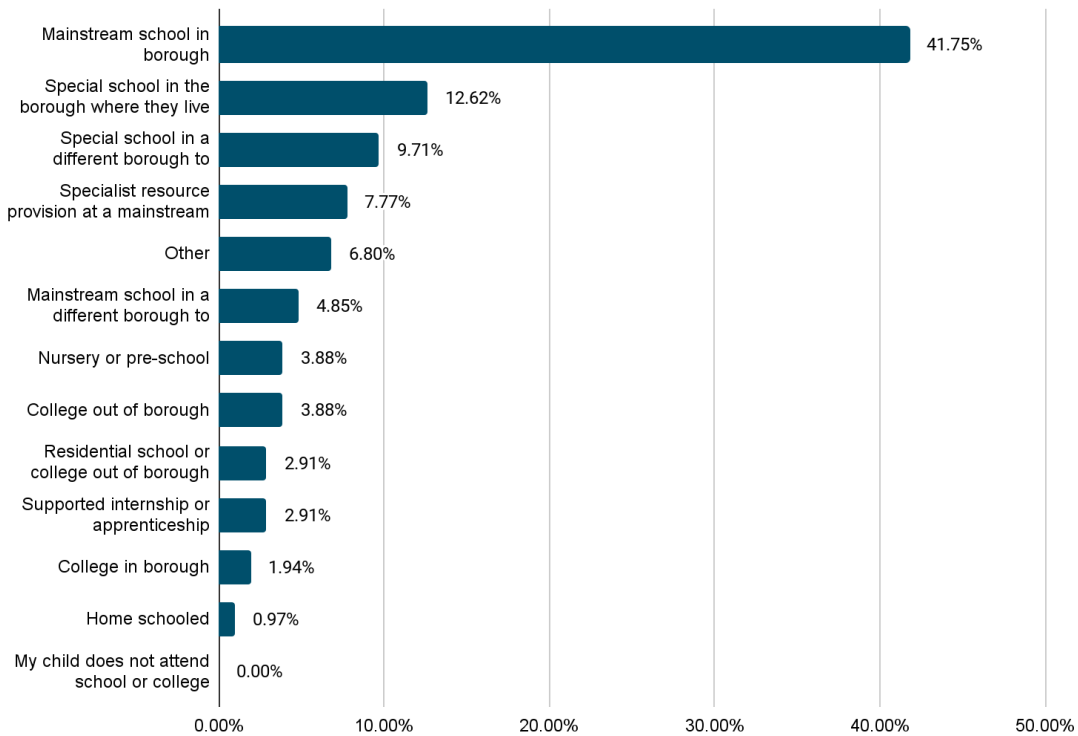
1. About the respondents

Which best describes your child/ the child you care for



In this survey, the sample is weighted towards parent carers whose children have an EHCP (66.67%). Whilst underrepresented (25.71%), those without an EHCP are still represented in this survey.

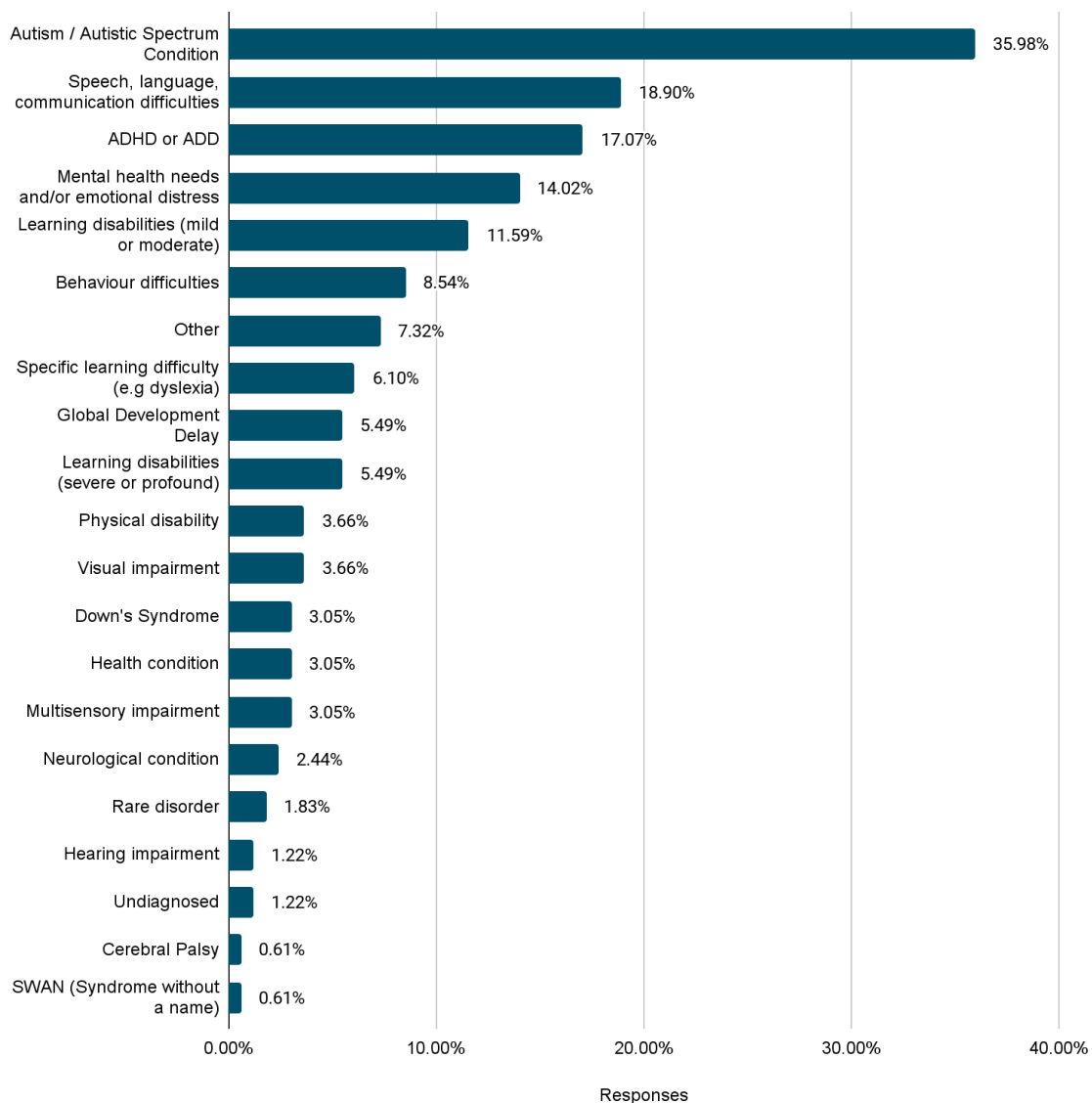
Which of the following best describes your child's/ child you care for education or training stage now?



The largest cohort within this sample are parent carers whose children are receiving education and support within mainstream schools; however the sample includes a wide range of educational settings. Parent carers whose children are not in education are however not represented within the data.

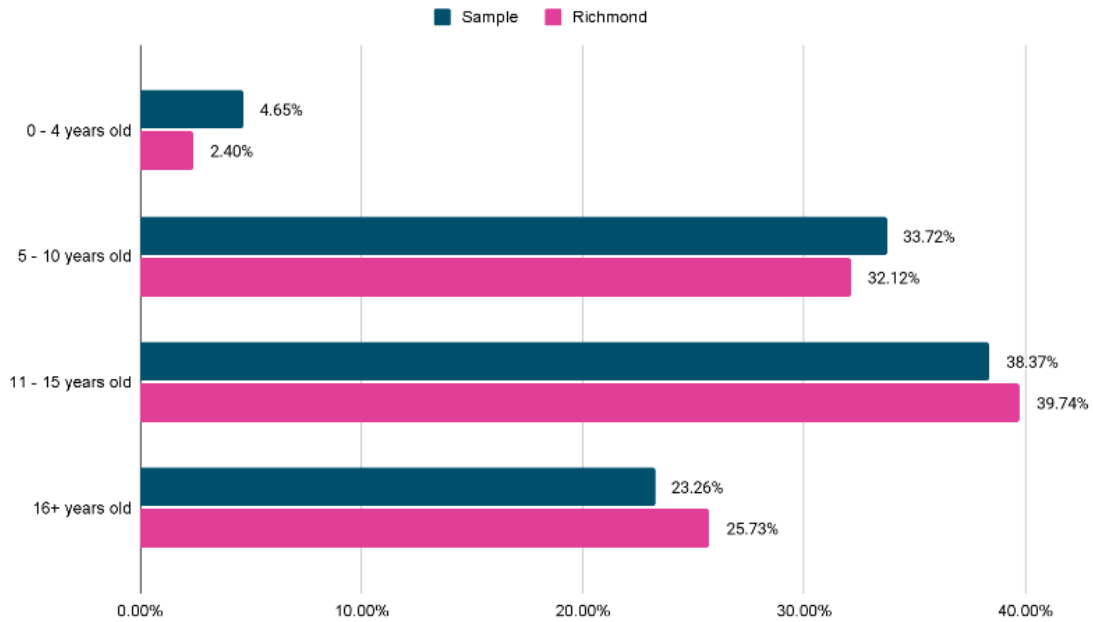
While parent carers were able to select multiple conditions, ASC and ADHD were the most frequent. Nonetheless, a wide range of educational needs and disabilities is represented. We do not have data to compare this with the figures for Richmond.

Responses vs. Please tell us about your child's/ child you care for diagnosis / special educational need.

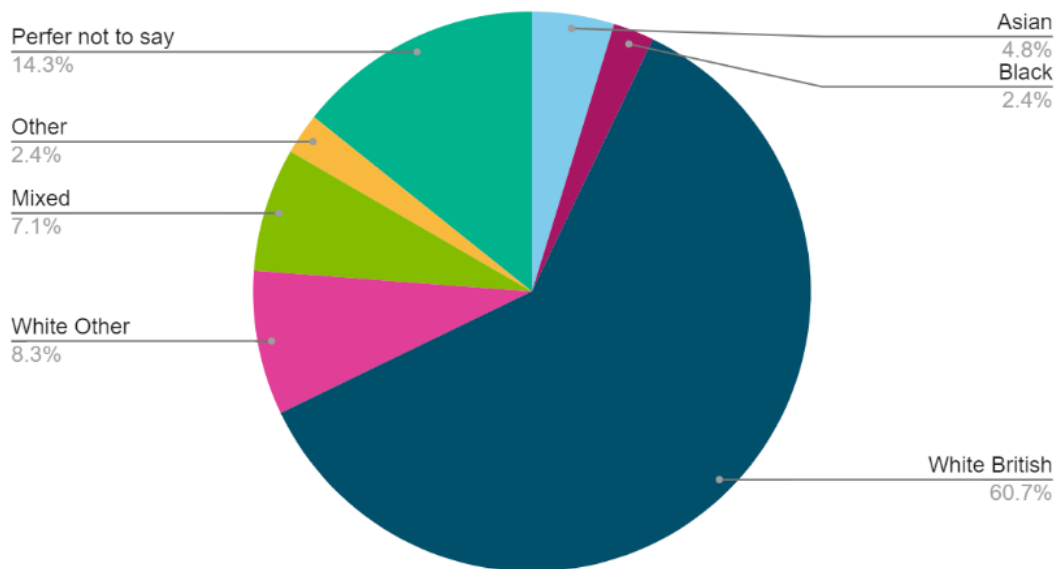


The age and ethnicity profiles of the data are reflective of the SEND community. People from Asian backgrounds are slightly underrepresented in the sample (Sample 4.8% vs borough average 8.9%).

Age of Children to which Feedback Relates

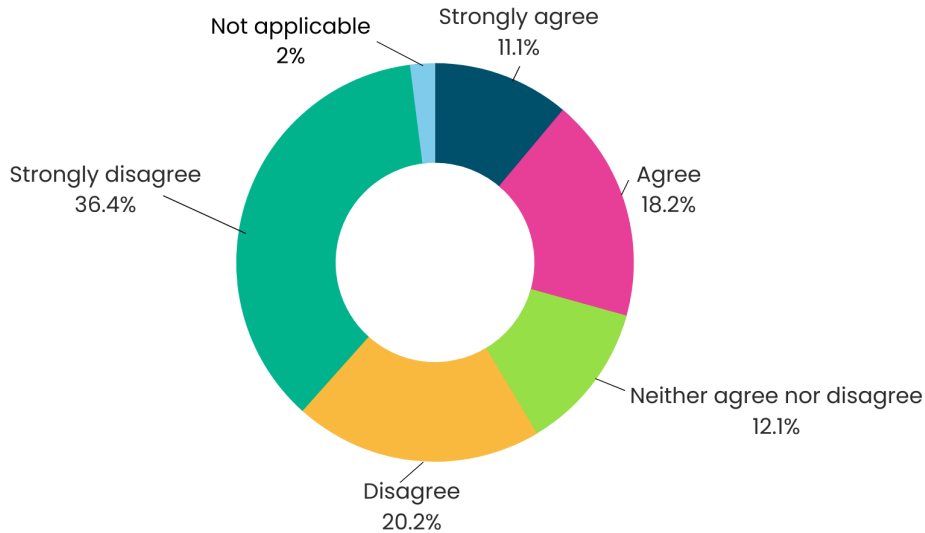


Child's ethnic background



2.1 SEND identification and assessment

Overall the child's needs were identified accurately and assessed in a timely and effective way



When professionals were sympathetic to the child's needs, parent carers felt that the diagnostic process worked well. This is reflected within the most recent Ofsted/CQC inspection which stated that:

"Most children and young people with SEND have their needs identified accurately and assessed in a timely and effective way"

Where things worked less well, respondents often spoke of gaps between the assessed needs and the support provided for children with SEND. Parent carers suggest a need for streamlined processes, improved communication between schools and parent carers, better access to early intervention, and increased staffing and resources to address children's needs in a more timely and holistic manner.

Delayed Assessments and Diagnosis

Parent carers with positive experiences were generally those whose children were diagnosed early. Parent carers felt that the team working on their child's EHCP had

good intentions; however, good experience of assessment did not always lead to effective support.

"My daughter's needs were well identified but the provision needed to meet those needs was not always well worded"

"Assessed and diagnosed well at 2.5 years but no support offered after this. I had to research and learn what was on offer. No signposting."

Other respondents expressed concerns about early assessment and intervention paths, especially for younger children. Delays in accessing assessments and services for children with SEND were also noted within the most recent Ofsted/CQC report:

"Some children and young people with possible autism or attention deficit hyperactivity disorder wait too long to receive a diagnosis."

As a result, some parent carers turned to private assessments due to long waiting times or difficulties accessing NHS services. This expedited diagnosis but imposed a financial burden.

"My [child] was diagnosed with ADHD in spring 2022, after having asked school for support for 4 years. She then was diagnosed with dyslexia winter 2022. Both diagnosis had to be done privately as otherwise we would still be waiting"

The consensus was that early intervention and timely support are crucial for children with SEND, with parent carers criticising delays in assessments and interventions. Some participants argued that early intervention is especially important as it prevents escalating problems and ensures more positive outcomes. Concerns were expressed about assessments narrowly focusing on one aspect of a child's needs, leading to incomplete support plans. However some parent carers had positive experiences of diagnosis and assessment.

"It was assumed my [child] had Autism despite me fighting for years to explain there was a lot more specific medical needs. These were never addressed except painstakingly by myself and support from GP and finally a diagnosis from GOSH"

“Long wait times, misinformation/ conflicting information from school, uncertainty led to increased anxiety for both child and parents, lack of meaningful support from anyone led to feelings of isolation”

“My child’s physical needs were assessed in a timely way”

Participants advocated for more individualised support and personalised approaches, recognising that each child's needs are unique. There were calls for better understanding and addressing the specific challenges faced by each child, rather than following a one-size-fits-all approach.

Navigating a Complex System

Parent carers often felt overwhelmed by the complexity of the assessment and support system, causing confusion as they sought to navigate various services, agencies, and professionals. The need for proactive and clear guidance on accessing assessments, services, and support was highlighted.

“School highlighted issues in year 3 and we went to the GP. CAMHS suggested that my child did not meet the criteria for assessment. We then got a private diagnosis during year 4. After that we applied for EHCP and the LA sent out specialists into school. None of them were in any doubt about my child’s difficulties. The plan was finalised in year 5. CAMHS has since supported a course of counselling. This means there was quite a long time while this all went on.”

“Lots of forms and bureaucracy while we were dealing with navigating NHS while trying to get his/her medical issues diagnosed. The families that need the most help get the least.”

Professional experience

Professional respondents to our survey told us that parent carers reported varied experiences with the accuracy and timeliness of identifying and assessing their children's needs. Some felt that children's needs weren't effectively managed. Lengthy waiting lists for services like SALT and CAMHS worsen the delay, compounded by changes in coordinators that require extra parental effort. The

assessment process itself is slow, and accessing appointments for necessary services proves challenging.

Professionals also reported that some families encounter resistance from schools to pursue EHCPs, even for academically struggling students, citing school pressures as barriers. CAMHS neurodevelopmental assessments face complexity and resource shortages, causing significant delays. Diagnoses are prolonged due to waiting times and lack of information, leading to SEND support rejections, causing frustration. Primary schools generally succeed more in assessments and support plans than secondary schools. Triage-based referrals involve online or in-person assessments, with Multidisciplinary Team Meetings crucial but contributing to delays.

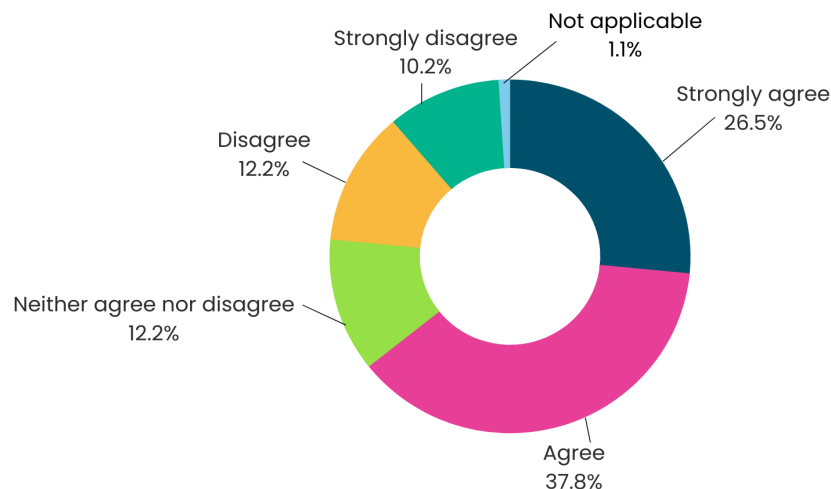
“In my experience parents of children with additional needs have very long waiting times for assessment. Also once assessment has started they are having difficulty accessing speech and language /occupational health appointments.”

“Pathway in CAMHS from screening to assessment for neurodevelopmental issues is long, complicated for families to navigate, under resourced and needs reviewing due to demand.”

Suggestions for improving services include clearer criteria for allocation and a more streamlined triage process. Waiting lists are a reality due to high demand, affecting diagnosis and assessments as mentioned above. Paper-based forms can create barriers to effective communication and working. Overall, families and professionals face challenges in obtaining timely and accurate assessments, with improvements needed across various stages of the process.

2.2 Parent carer involvement in decision making about their child

Overall I am actively involved in decision making about their plans and additional support



Parent carers highlighted the collaborative approach taken by professionals to support their child and efforts to involve them in decision making about their child's support. This is reflected within the most recent Ofsted/CQC inspection:

“Children and young people with SEND benefit from professionals who get to know them very well. EHC plan case workers, social workers, therapists and education staff take time to understand the needs of children and young people and consider how best to support them and their family”

Respondents also provided a range of experiences, opinions, and challenges related to the provision of support and services for children with SEND, from the lack of understanding among professionals, to the need for better communication, more transparent processes, and more adequate support and resources. The responses also highlight the pivotal role that parent carers play in advocating for their children and ensuring that they receive appropriate and effective support.

Mixed Experiences

Some respondents report positive experiences with supportive staff involving them in their child's support and progress over time.

“SEND support at school is good, they have been communicative and schedule appropriate parents meetings and EHCP reviews promptly.”

“We get recommendations from Ed Psych, OT, Clinical Psychologist and discuss with school. This has to be reviewed and tweaked occasionally. I am actively involved.”

“Support from school has been invaluable over the years but it is a constant battle with the LA.”

Several participants highlight challenges in obtaining appropriate support from schools. This includes instances where schools downplay a child's struggles or fail to follow IEPs. Some respondents stress the importance of focusing on social communication and peer relationship skills in addition to academic support.

Other parent carers face challenges, suggesting variability in the quality and effectiveness of support services. Respondents express a lack of trust in the system, citing past negative experiences and feeling that they need to oversee every aspect of their child's support. For some, there was a perception of LAs not being responsive and some concerns about LAs making decisions that may not align with the child's best interests and disregarding legal requirements.

“Things are improving over the years but a lot is to do with who one has as a case officer. The 2 supervisors need to be made more responsible for their actions as sometimes they completely ignore the SEND code of practice - if they know the SEND law then they should abide by it if they don't then they need to be trained and tested on it regularly.”

Lack of Understanding and Expertise

Some respondents had very positive experiences of services such as SENDIASS in supporting their children's needs. This is reflected in the Ofsted/CQC inspection report:

“The local area provides extensive training for education staff so they have suitable knowledge and skills to support children and young people with SEND very well.”

Others said that professionals were lacking knowledge and understanding of specific conditions, such as Pathological Demand Avoidance or ASC. There is a perception that professionals without proper training dismiss parents' insights and opinions, leading to inadequate support and decisions that may not align with the child's needs.

“Sendiass were fantastic and had an excellent understanding (have not contacted them since the provider changed). I think all staff need to understand autism from the perspective of autistic people and have this at the forefront of interactions. It still feels that many autistic people are required to mask to navigate through education, health care appointments etc. Any therapies for autistic people should be autism friendly. Autistic children and their parents/carers should not be gaslighted.”

Parent Carer Advocacy

Many described being persistent advocates for their children, seeking attention and pushing for assessments, diagnoses, and appropriate support. Parent carers often felt the need to navigate the system on their own, taking proactive steps to meet their child's needs and obtain proper support and services for their children. This involves navigating a complex system, pushing for necessary interventions, and educating themselves about their rights and options. Respondents expressed frustration with bureaucratic processes, lengthy waiting times, and a lack of clarity in navigating the system, including delays in obtaining assessments, EHCPs, and support services. There were mentions of legal battles, tribunals, and the stress of having to navigate complex systems to secure services.

“We have always had to push school for meetings, for interventions and for action plans”

“The process of applying for an ECHP and working out school options is hugely confusing. It took two (highly educated) parents to really research it all and seek voluntary (RUILS) and peer support”

Communication and Collaboration

Lack of proper communication and collaboration between some schools and parent carers was noted as a barrier to identifying and addressing SEND effectively. Some respondents praise schools that involve them in the process and value their input, while others mention tokenistic involvement. Some schools were described as resistant to initiating assessments or providing necessary support, resulting in children falling behind.

The importance of effective communication and collaboration between parent carers, schools, and professionals was highlighted throughout the responses in this survey. Many respondents emphasised the importance of involving parent carers and caregivers in decision-making processes. They want their voices to be heard and valued, advocating for collaborative efforts between schools, local authorities, and families to ensure the best outcomes for children with SEND.

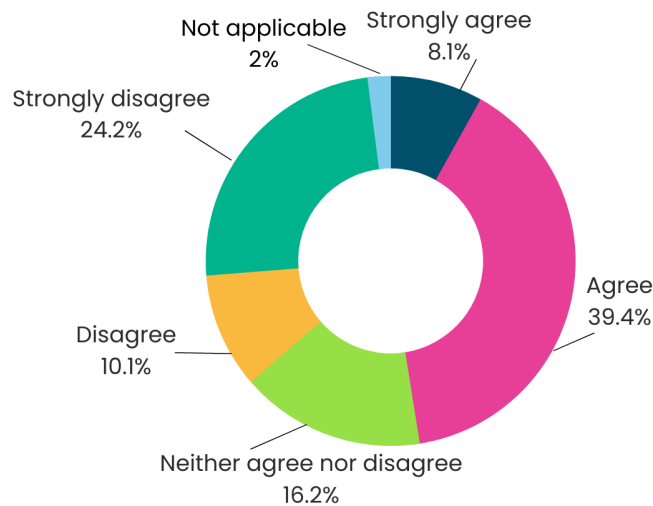
“The whole system needs to be transparent and involve parents and children more at every stage. We like to be informed and are part of the team.”

Professional Experience

The professional respondents lacked direct decision-making authority over young people's needs but possessed knowledge about processes and services, offering advice to parents. They engaged with schools to improve support for shy or embarrassed youths, advocating for staff training to identify ADHD or ASC signs. Networking, meetings, and sharing contacts post parental consent were their strategies. Some influenced decisions via trust-building, communication, and reassurance, mainly in mental health services rather than school SEND support, though aiding in NDT referrals and EHCPs. Weekly MDT meetings involved case presentation, discussion, and multi-step decisions for complex cases. They emphasised increased caregiver support for complex needs and highlighted collaboration, communication, training, and caregiver assistance as focal points based on their feedback.

2.3 Perception of help and support received

Overall the support and help the child receives is the right help delivered at the right time:



In terms of perception of support, there were stories of both success and struggle. There were several references to the importance of good support in schools which was perceived as having a particularly strong impact on children's wellbeing. Delays, inadequate resources, the need for consistent communication, and the significance of personalised support plans were also common themes throughout the responses.

Resources, Quality and Service Delivery

Several parent carers reported that support in school was particularly effective and valued by both children and parents.

"I feel that overall is good, but I would like him/her to have a bit more support around self-regulation, social skills etc. S/He also really struggles with his attention at school"

"Good VI [Visual Impairment] team that support my child very well in school."

“My[child] is currently well supported at school. We are very fortunate that she/he was placed on an SRP as I’m aware there is huge need for more of these placements across the borough”

There were reports of inconsistent service provision and assessment outcomes. Several parent carers believed the lack of resources and high staff turnover, particularly within support services, hindered effective assistance. Respondents felt let down by delays in accessing appropriate support and services for their children. However they were generally sympathetic to the constraints professionals within the services had to work within.

“There are not enough resources for the complexity of needs required to support children with additional needs. Despite going to a specialist school, with on site support for OT, S&L, etc, these resources aren’t adequate/sufficient enough to support the actual children individually.”

Parent carers further highlighted the need for increased funding for SEND services both in schools and externally, which they believed to be crucial for effective interventions. Many were concerned that lack of funding led to cutbacks in support services and clinical input. A recurring sentiment was promises of support not being fulfilled. As noted earlier, several parent carers relied on private interventions to supplement school support. Overall there was a feeling of unfulfilled promises of support, unresponsiveness from local authorities and challenges in contacting social workers.

“The policies and behaviours of AfC and the council appear to be purely based on saving short term funding and are not about the needs of the child or the wellbeing of them and their family. The policies such as refusal to assess when the child clearly meets threshold is beyond damaging”

“Individually, I believe staff are doing their best within a very broken system. If there was a mechanism by which they could work together i.e. a true ‘Team Around Child’ culture that would help a lot. Education, health and care operate in silo’s due to the construct of the infrastructure. This needs to change, along with funding and a mandate to reach all children in need i.e. true early intervention.”

Limited availability of therapists and professionals, due to budget constraints, persisted as a recurring issue. Several participants reported wanting better or continued access to OT's. Either because their child had them or because they believed they could benefit from them.

"Speech and language and OT have been great in giving information regarding support and strategies."

"I'd like my[child] to be able to access more regular speech therapy and OT provision."

Several respondents expressed a desire for improvements in CAMHS. Parent carers of children who had utilised the services had positive experiences. Those who had not accessed the services felt the waitlist was long and there was a lack of follow up.

"CAMHS are supportive and respond to emails quickly."

"Since my child's ADHD diagnosis, I have had no follow up from CAMHS. It is fortunate that she is at a better school for SEN support but I don;t know what else is available to support my child."

Individualised Support and EHCPs

While EHCPs have been positive for some parent carers, the process is a point of contention for many due to delays, inaccuracies, and lack of adherence to legal timelines. Some parent carers stress the importance of professionals understanding their child's EHCP for appropriate support.

"The process of requesting an EHCP was very stressful and having to wait for OT/SALT and especially the EP input took a long time. The EHCP was assessed and issued within the stated timeframe which was positive."

Several respondents found the EHCP process complicated and difficult to navigate with a need for clearer, actionable information about the process.

"My [child's] first request for assessment was denied even though the community paed had told us she needed a specialist setting for severe"

special needs. It took over a year to get her/his EHCP. Lots of forms and bureaucracy”

Successful outcomes were often linked to well-structured, detailed plans addressing a child's unique needs. However, parent carers highlight challenges in waiting for therapy, EHCPs, and interventions, leading to worsening conditions and missed opportunities.

“My child's physical needs were assessed in a timely way, but his emotional, sensory and mental health needs have not been adequately reflected in his EHCP and it is very challenging trying to get them to be properly recognised and supported”

Alongside EHCP, participants also emphasised the need for inclusive education environments and accessible services for children with SEND. This included providing reasonable adjustments, and ensuring that all children have equal opportunities to learn and succeed. There was positive feedback from parent carers on schools and educators who prioritise the well-being, support, and inclusion of children with SEND, offering a supportive environment, celebrating strengths, and providing targeted interventions to help children with SEND succeed.

“I have always been invited to EHCP reviews and been actively involved in plans about support for my child's education.”

“My child's nursery have been great at allowing me to have massive input and opinions in the EHCP application process.”

“Our child has an EHCP which provides funding for a one to one teaching assistant for our child in their learning at school. Our child is also familiar with the other teaching assistants and the class teacher (and vice versa). The teachers have made a great effort in adapting a learning space for his/her needs, so that she has access to fidget toys, her/his own desk, a visual timetable, visual prompts etc.”

Mental Health and Wellbeing

Parent carers highlighted the importance of integrated mental health support and early intervention for emotional wellbeing. Some respondents discussed the impact of delayed or insufficient support for their child's mental health, including instances of anxiety, depression, and emotional struggles, often exacerbated by the lack of timely intervention and diagnosis. Respondents also expressed concern about SEND-related challenges affecting children's self-esteem, happiness, and quality of life, with the impact on mental health being a recurring concern.

“Being undiagnosed for so long without appropriate help has had a huge impact on her/his mental health, s/he has general anxiety disorder and OCD, a very low self esteem and no confidence. S/he cannot go to school some days due to his/her anxiety.”

“There is help to a certain extent but if you need more there is nothing. School is only interested in child's performance much less so mental health.”

A few respondents mentioned the mental health and wellbeing of both children with SEND and their parent carers, calling for more mental health support services, including counselling and well-being programmes, to address emotional challenges associated with caring for children with SEND.

“I had to go off work with stress as I could not work in Central London and care for my child at home, I have 2 other children whose quality of life has been significantly affected, and I am a solo parent who also cares for my elderly mum and the impact on my mental health has been huge. My child hardly leaves her/his bedroom and I am now virtually a prisoner in my own home.”

“Wearing parent carers down both mentally and physically does not help - in the end it puts more demand on the health services as parent carers need help as well as the young adults.”

Professional Training and Education

Participants highlighted the importance of ongoing training and education for professionals, encompassing teachers, support staff, and healthcare providers, to understand and support diverse needs. It made a significant difference to parents when teachers and other professionals were well informed. The general emphasis from parent carers was that increased awareness and understanding of SEND conditions can lead to better support and inclusive practices. Moreover, a recurring theme was wanting professionals to exhibit more empathy and sensitivity when interacting with parent carers and children with SEND. Participants desired professionals to listen and understand concerns without judgement.

“Not all teachers have the knowledge and understanding of this condition (ADHD) , and may be unsympathetic. This is clear and more training is required for teachers, in general.”

“Lowther primary school Reception teacher. They noticed (the child) did not follow instructions very well. Slow to process. Slow to speak and read. Their system Worked very well. They supported her, compiled the evidence they needed and applied for EHCP”

“The biggest single thing that could have made a difference would be better training of neuro-diverse conditions within primary school staff so these can be picked up at the earliest stage and supported. This would have enabled us to make different choices at secondary school (where there was also woeful ignorance and support). The GP also needs better training to spot signs and signpost at an earlier stage.”

Professional Experience

Professionals noted that specialist schools can face pressure to retain students despite inadequate care, worsening behavioural issues and making suitable placements hard to find. Differentiation in short breaks is proposed for varied needs alignment. Parents struggle with documenting and implementing therapies like OT and SALT in EHCPs, finding the local offer overwhelming to navigate without guidance. The SEND system often waits until children struggle before providing help,

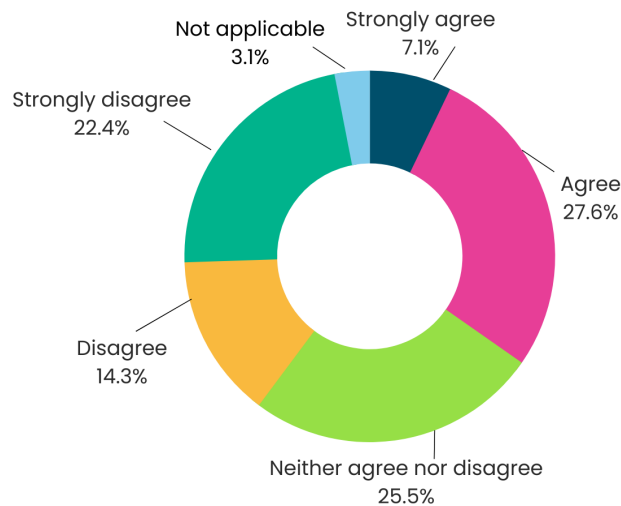
and visits from specialists to schools can be unproductive due to resource shortages. EHCP acquisition is time-consuming, with complex plans leading to unmet needs and emotional vulnerability.

“Many parents do believe that their young person is receiving the support they need at school but equally many others feel that it is not adequate. I generally do not hear a happy story about therapies - eg OT, SaLT - with parents struggling to get any written into the EHCP and then struggling to get it actually provided.”

Support is occasionally delayed, and MDT interventions can have prolonged waiting times. Parents resort to private options due to extended support timeframes. Overall, concerns encompass insufficient resources, delayed support, and system navigation challenges for both parents and professionals.

2.4 Preparedness for changes in education and life

Overall the child is and has been well prepared for changes in their stages of education and work:



While some participants praised schools and professionals for their efforts, others expressed concerns about inadequate support, communication gaps, and challenges related to EHCP implementation during transition periods. Clear communication, collaboration, and tailored support emerged as essential factors for successful transitions for individuals with SEND.

Transition and Support in Education

Respondents had mixed experiences with educational transitions. Concerns were raised about insufficient preparation, support, and coordination during transitions, particularly from primary to secondary school.

“He received excellent support via portage, VI teacher at home prior to starting school, smooth transition into preschool with portage support, EHCP, specialist setting out of borough, specialist college out of borough. Transition to adult support could be improved”

“Not much transition from Year 11 to Sixth Form at a specialist provision. It was the best placement we could find as local mainstream college was very negative taking [the child] and he/she couldn't stay on at school unless he/she did A levels. There is still a huge gap for students who aren't A level material but aren't yet mature enough to start work at age 16”

Participants highlighted the significant role of individual schools in the transition process. Some respondents reported positive experiences with certain schools, praising their support and preparation efforts, while others expressed dissatisfaction with the lack of support and inadequate training for teachers. The quality of transition support seemed to vary based on the school's approach and willingness to collaborate with parent carers and professionals.

“Transition from primary to secondary was done very well indeed by school and by the LA transition lead. The additional sessions within the school (not just one day) helped make transition work well.”

“Teachers past and present have worked well with transitions and planning these for our children. Our SLT has been good at providing tools and resources to aid in transitions, such as social stories etc.”

While some parent carers reported valuable support from social workers and case officers, others expressed frustration with inconsistent support, lack of timely response, and overreliance on parent carers during transitions.

“The social team rely on parents to do everything. Supported living does not exist - the transition team were given 4 years notice to get their act together and nothing has happened. A transition care assessment still has not been [done]”

Participants also highlighted the need for accessible resources, such as visual aids, transition guides, and training materials, to support children with SEND in understanding and adapting to new environments.

“Struggles to understand big changes, however if there was more accessibility to visual cards or even somewhere to point parents in the right

direction of where to buy things like visual cards, now and next boards this might make this easier.”

Mental Health, Anxiety and Concerns

Some parent carers expressed feelings of anxiety and concern regarding their child's transition, particularly from primary to secondary school. Anxiety was linked to uncertainties about the new environment, teachers, routines, and the level of support provided.

“I don't know but feel anxious for [my child] starting secondary”

Parent carers also mentioned that their children experienced heightened anxiety during transitions, impacting their overall well-being. Some participants shared experiences of bullying and poor mental health outcomes for their children during transitions. Schools were sometimes criticised for not adequately addressing these issues and providing the necessary emotional support. Bullying and mental health concerns were particularly highlighted in the context of secondary school transitions.

“After school started, the children were not monitored and there was no additional longterm support. Both my children were severely bullied at their secondary school, one so severely that s/he developed a tremor in his/her arm and PTSD, the other experienced a mental health crisis and now has longterm mental health problems”

Communication and Collaboration

The importance of effective communication and collaboration among parent carers, schools, LAs, and professionals was emphasised. Parent carers highlighted the need for consistent updates and transparent communication throughout the transition process. Schools that actively engaged were viewed as important to the success of transition.

“Excellent transition into primary school, plenty of time to adjust before going full-time, lots of support all the way through. Good transition from primary to secondary. Lots of extra transition contact and activities. Time to become

familiar with the staff at much bigger school and to get to know the LSAs and the Senco."

"Absolutely no help to transition, was a battle to be taken seriously. And still on going. No communication from nursery to reception and no communication from reception to year 1"

"The transition to adult services was horrendous. I found it the most upsetting experience but this was from the social service side. I never want to go through something like that again - the manner in which I and my [child] were asked questions was insensitive the discussion the social worker and the nurse had in our presence was offensive it brings me to tears to think about it"

EHCP Issues

Parent carers were disappointed over delays in EHCP assessments and implementation, leading to a lack of timely support during transitions. There were instances where EHCP goals were not adequately addressed, impacting the transition process.

"Don't think the outcomes sought in the EHCP were met. Not enough feedback from the school. Not enough focus on the EHCP goals"

"The EHCP itself has been in the system for 14 weeks without being returned and we are not able to prep our child for the next phase of transition as there are no secondary schools that can provide his support in the borough."

Concerns were raised about the lack of consideration for clinical services and therapeutic support in the EHCPs, which was crucial for some individuals with intensive needs.

"Well, all clinical services have been cut from his EHCP, and no reason given. No suitable placements has been suggested. Nor has it been covered how somebody who has needed intensive clinical input and support in special school will be able to cope with no clinical, support in a mainstream setting."

These concerns are reflected within the Ofsted/CQC report:

“Children and young people’s EHC plans are not consistently updated. There is variability in how well EHC plans capture the current needs of the child or young person and have appropriate outcomes. In some instances, this is due to a lack of contributions from the range of professionals involved with the child or young person with SEND. This can impact negatively at key transition points for some children and young people with SEND as their EHC plan is out of date and contains inaccurate information.”

Preparation for Adulthood and Training Needs

The Ofsted/CQC inspection found that:

“Most young people are prepared well for adulthood. They receive helpful carers advice and guidance about the options available to them, including apprenticeships and supported internships. Health and care practitioners work closely with adult services to ensure young people with SEND transition well through comprehensive handovers.”

Parent carers highlighted the need for better preparation and training programmes for individuals with SEND during transitions. There was a call for more guidance, services, and support systems for those entering post-16 education, higher education, apprenticeships, jobs and life skills training. In addition, clearer guidance regarding applications, support mechanisms, and resources was viewed as important to help them understand available options and vocational paths suitable for their child's needs.

“The local options are very poor largely basic work skills 2/3 days a week -he is way beyond this. The idea is that for the days without training our kids can do a couple of very dull activities whether or not they have any interest in them or just sit at home”

‘There are no links to good training schemes which are able to provide support and encouragement. There are no links to local business for

placements. There is no energy and imagination. It's incredibly poor. We are terrified at how meagre the future is for our[child] and so is s/he.'

Professional Experience

Professionals stress the need for increased resources in specialist schools to aid young people's transitions and highlight the lack of information regarding post-16 living options, internships, and work experiences. Parents play a pivotal role in decisions about future education, but often lack support and information during these significant changes. The transition from school to college is particularly tough, requiring independent exploration of options. Respondents note unfamiliarity with supported living and adult social care options among parents, with limited availability of supported living placements.

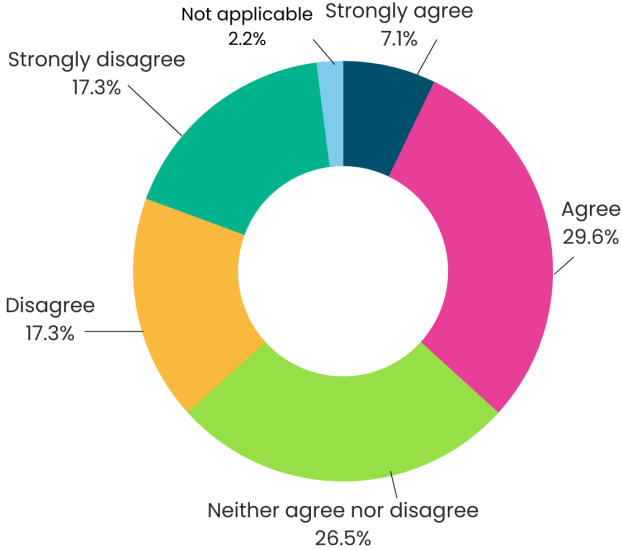
"Very few parents know much about supported living or whether this will even be an option for their young person. Most parents I work with have not had support from children's social care and know nothing about adult social care and what options there might be for their young person."

Healthcare and mental health support during transitions are problematic, often leading to unclear plans and GP referrals. While some schools have robust transition processes, challenges like assessment delays impact transitions. Primary to secondary school transitions are well-supported, but post-16 and post-18 roles require more preparation. In particular, challenges arise for students who refuse school and later struggle to re-enter education or work. Communication gaps between schools and homes persist despite professional efforts. Improved coordination and clarity among services is recommended to enhance transition support.

"Children going from primary to secondary school are well supported and prepared for this change, however I think young people going into post 16 and post 18 roles need more support and preparation about what to expect and where they can go for support."

2.5 Involvement wider community activities

Overall the child feels valued and included within our local community:



Social and Community Inclusion

The CQC/Ofsted inspection reported that:

“Children and young people with SEND have a variety of opportunities to participate in activities within their communities.”

Parent carers expressed a desire for more inclusive practices within schools, as well as opportunities for children with SEND to engage in social activities, sports, and other extracurricular activities. Parent carers expressed concerns about the lack of inclusivity and support for individuals with disabilities within the local community. Among respondents there were mixed experiences of community participation, with some individuals having limited opportunities to engage in activities due to challenges in finding suitable programmes or the absence of an appropriate offer. Participants also reported the need for more activities they could participate in as a family.

"I contacted a ballet class that said that they had a class for SEND children and were supportive and inclusive. (...) This person never responded to messages (phone and email) and still runs ballet classes in Richmond, and still has a website saying that they are inclusive and support SEN children. Unfortunately this is often the approach we have received. They say the right words for kudos but don't want to have your SEN child in their class/group."

"There are very few things that my child could be included in in the local community due to his need for simpler instructions, routine and lower than average physical ability"

"I think the resources in terms of school placements are absolutely incredible. The only negative comment I can make is that there are not enough resources for after school and weekends. It can be very isolating for the child and carer. Playgrounds are always a challenge. Maybe having 'set times' that SEN children can access playgrounds. This would enable them to enjoy the space without judgement"

Many parent carers experienced a lack of recognition and celebration of disabilities within the community, particularly during events and awareness campaigns. Generally it perceived that there was a limited availability of activities specifically tailored for preschool-aged children with SEND.

"Students with autism/disabilities are often not included nor celebrated, they're mostly in the background & hardly get noticed, they're forced to fit in rather than be themselves."

Parent carers reported taking on the responsibility of seeking out and organising activities and support for their children with SEND. Respondents expressed the need for more suitable activities, opportunities, and support available for young people with SEND, particularly during school holidays. There were also some concerns about the limited availability of programmes that cater to the needs of individuals with intellectual disabilities, sensory sensitivities, and complex needs or once children reach adulthood.

“Crofters club was amazing. However, it stops dead on a young person's 18th birthday and they were not able to help support my[child] into post 18 provision so we were on our own with that.”

Respondents also suggested improved training and awareness among professionals, teachers, and community members regarding the needs and challenges faced by individuals with SEND. There were also calls for a more inclusive and accessible offer, such as SEND-friendly swimming lessons, activities for teenagers, and non-competitive social events.

Social Interaction and Friendships

Parent carers often found that their children had difficulties in building and maintaining friendships, with some individuals experiencing social isolation and lack of peer connections. Many reported that their children had experienced instances of exclusion, and negative social experiences affecting individuals' mental well-being and self-esteem.

“He/she is sometimes laughed at and has no friends. It is miserable for her/him.”

“My child feels very excluded as an autistic young adult”

However, there were positive experiences reported of making friends through supportive environments, such as schools and specialised programmes.

“I think the specialist groups that he/she participates in also make her/him feel valued (21 & Co, OKMT, Brentford Penguins, etc), but I don't think AfC really sees her/him as an individual with needs”

Anxiety and Mental Health Impact

Parent carers highlighted that individuals with SEND can experience high levels of anxiety, which can lead to avoiding social interactions and organised activities. Some reported that anxiety-related challenges affect mental wellbeing, hydration, eating habits, and overall quality of life for both individuals with SEND and their families.

“Our child's anxiety was so extreme that at one point they did not leave the house for nearly a year (...). Our child does not feel comfortable in group situations with people they don't know meaning that they don't have very good access to their local community.”

Professional Experience

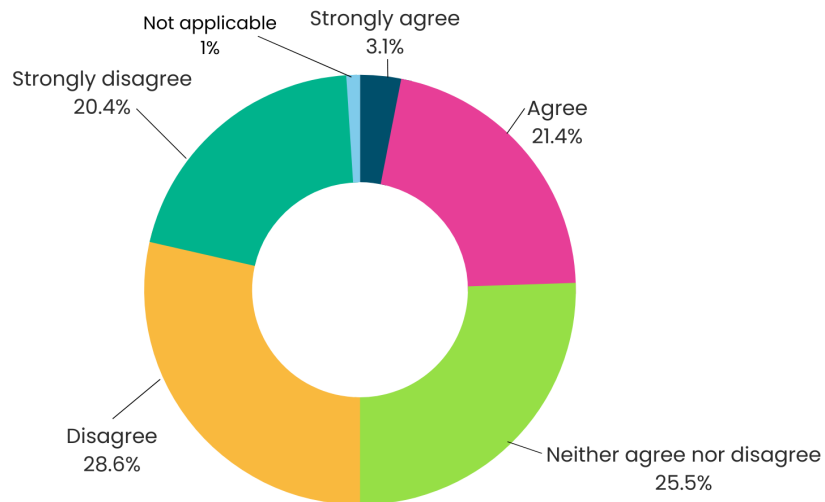
Professional respondents express concerns about the lack of active promotion of inclusion, citing challenges with school transport and an inconveniently located overnight respite centre in Chessington. The outdated playground at Moor Lane and insufficient investments for children with severe needs are criticised. Limited local friendships and community access, potentially due to social anxiety, are noted for some individuals. Parents are burdened with discovering suitable activities and left, feeling overwhelmed. Some parents perceive few options for young people not attending college, although providers exist; however, finding these options and transportation falls on families, potentially hindering independence. Professionals advocate for support systems to aid parents in navigating activities and fostering independence. Ham Youth Club is highlighted as a positive example of fostering a sense of belonging through activities.

“We work with Ham Youth Club and have seen how there is a sense of belonging in this youth centre, including young people with additional needs. They enjoy playing football, computer games and art - just to name a few of the activities this youth centre has to offer.”

Financial barriers exist for low-income households, and social anxiety hampers some children from leaving home. The supportive nature of Heatham House is recognized by young people.

2.6 Quality of support information

Overall I am happy with the quality and accessibility of information relating to SEND:



The responses emphasise the importance of providing families dealing with SEND-related concerns with clearer, easily accessible information, proactive communication, and practical support to address these concerns effectively.

Lack of Clear Pathways and Information Access

Parent carers expressed difficulty in understanding the pathways and processes related to SEND provision. They highlighted the need for clearer guidance and information.

"It is impossible to understand how to navigate the SEND provision."

"You have to plough through a lot and figure a lot on your own."

"There is an assumption that parents know where to look to find information - we do not have a crystal ball! We are expected to know to check webpages to know when deadlines are, when we have no idea that there are deadlines, as we have no experience of the SEND processes and are learning as we go. "

Some respondents mentioned that information is scattered across different platforms, making it hard to access relevant information easily. The lack of a comprehensive source for information on services, support, and available resources was a common concern. The lack of clear information and available services for older individuals with SEND was a recurring concern.

Reliance on Personal Networks and Online Communities

Many respondents felt there was a lack of clear communication and easily accessible information. They emphasise the importance of receiving accurate and timely information regarding their child's needs, available services, and their rights. There is a call for transparent, up-to-date, and user-friendly resources that parent carers can easily access.

“You cannot find things easily, the only way I find valuable info is by talking to other SEN parents or some charities. And you have to fight constantly for everything.”

Respondents often relied on personal networks, social media groups, and other parent carers to obtain information and navigate the SEND system. The importance of shared experiences and advice from others facing similar challenges was emphasised.

“I have a wide network of contacts in the SEND world so I can find out about what is available, but my[child] won't engage in social activities for YP with SEND so this is only useful in the education part of his life.”

“It feels like every parent/carer is having to work this out for themselves. There was no post diagnostic support. All information requires searching out information online and attending groups/charities if they have availability. It requires a lot of energy, networking and time when you are low on these resources.”

Communication and Engagement

Many respondents highlighted the need for more proactive communication from professionals regarding deadlines, processes, and available support. Parent carers felt that they needed clearer communication and better engagement from professionals to guide them through the SEND system. Lack of coordination and information sharing was seen to hinder effective support, leading to missed opportunities for early intervention.

“Case workers should be more proactive and communicate deadlines and processes - they are overly reliant on parents being able to navigate webpages which are not necessarily well designed or intuitive”

Some participants suggest using technology to create centralised databases of SEND resources and services, making it easier for parent carers and professionals to access relevant information. However they did not provide specific examples of how this could be done.

Issues with AfC Website and Information Design

Respondents expressed a strong desire for improvement in the design and user-friendliness of the AfC website. They found the current website difficult to navigate when searching for pertinent and succinct information. What they sought was a more efficient, condensed, and straightforward presentation of information. Additionally, respondents believed that parent carers possess valuable skills and knowledge that could be tapped into more effectively. They suggested that these skills should be leveraged to a greater extent. Some parents, particularly those with a keen interest in the subject matter and proficiency in IT, even offered to volunteer their expertise to contribute to the development of a new platform dedicated to providing SEND information and facilitating engagement.

“I would like to propose a website/app which has a complete database of all SEN resources including schools/colleges, activities, socialising”

However when information was located it was generally found to be useful.

“The local offer website is good, but needs better delineation and clearer categories”

Professionals highlighted the challenges parents of young people with SEND encounter while seeking information and support. The abundance of overwhelming information on websites makes finding specific details difficult, and though the local offer is comprehensive, it can be intimidating without available assistance. Contacting organisations for resources is laborious, as parents lack clarity on necessary information. While information is important, personalised help in navigating it is desired, and some respondents note useful websites for SEND information.

“The local offer has a lot of information on it but it can feel overwhelming to parents and there generally isn’t anyone the parent can ask questions of. It’s a lot of work for a parent to contact each individual organisation that might have potential.”

Schools are praised for supporting SEND children, but suggestions for improved parental education and support are made. Positive experiences involve valuable information and effective collaboration, while challenges stem from extended wait times for in-person professional interactions. Overall, the responses underscore the need for easily navigable resources and personalised guidance to aid parents in accessing relevant SEND information and support.

3. Conclusion

This report sheds light on the experiences and challenges faced by 103 parent carers and 21 professionals and service users of SEND services in the borough of Richmond. Through their voices, our research has highlighted key areas that demand attention and improvement.

We are clear that the methodology used in this work does not allow conclusions to be drawn about the current quality of the SEND services from this report because we have made no attempt to separate historic and current experiences. That AfC have sought out feedback from as many people with experience as possible, and partnered with ourselves to do so in an independent and unbiased manner, to inform the development of their services should be viewed positively. The recent positive Ofsted/CQC report should be taken as assurance as to the quality of AfC's work.

While recognising the successes and positive outcomes resulting from supportive school environments, personalised plans, and cooperation between stakeholders, the report highlights the systemic challenges that have been experienced by service users, parent carers and professionals. These include delays in assessments, inadequate resources, and difficulties for families and careers to navigate the system. In addition, difficulties of transitions between educational stages and adulthood remain significant hurdles. The report underscores the importance of individualised support, effective communication, and collaborative practices among professionals and within communities.

The responses demonstrate that early intervention, proper training and awareness among professionals, and readily accessible information and resources are pivotal for ensuring the holistic well-being of children with SEND. Additionally, the report emphasises the significance of recognising and celebrating the unique abilities of individuals with SEND, fostering a more inclusive and understanding community.

As we have highlighted in the report, addressing these challenges requires streamlined processes, enhanced communication and collaboration between schools and parent carers, as well as timely access to interventions. Furthermore, the survey responses have brought to light the complexities involved in transition

processes. Effective transitions require clear communication, collaboration, and tailored support. Where these exist, people report a successful progression of individuals with SEND into new stages of life.

Ultimately, this report serves as a call to action by parent carers. It calls attention to the importance of improved communication, increased access to information, and investment in resources to facilitate the optimal development and wellbeing of children with SEND.

The experiences shared within this report highlight the resilience of parent carers, the commitment of many professionals, and the potential for positive change when the system works collaboratively with them to build an inclusive and supportive environment. The challenges of the financial and workforce environment are also clear.

In moving forward, the insights and recommendations presented in this report should guide policy, resource allocation, and community engagement opportunities. By addressing the challenges highlighted within this report, meaningful, tangible steps can be taken towards creating an environment where every child, regardless of their abilities, can thrive, learn, and contribute to society in Richmond and beyond.