



# Integrated Care System

Shropshire, Telford and Wrekin

**February 2024**

## Shropshire November 2023 Parent Carer Survey Report

# About the survey

- In Summer 2023, the Shropshire Local Area put out a survey to understand the experiences of parent carers who have neurodiverse children and young people (CYP), parent carers of CYP with Speech, Language and Communication Needs (SLCN) and parent carers of CYP with an Education, Health Care Plan (EHCP) or going through the Education Health Care (EHC) process.
- The intention of the survey was to establish a baseline of people's experiences to enable the Shropshire Local Area to measure the impact of the actions it is taking against the Special Educational Needs and Disabilities (SEND) Accelerated Progress Plan.
- There were 205 responses to the survey, which ran from August to September 2023. The survey asked about both historical and current experiences of parent carers.
- 138 responders were parent carers of CYP who required support related to neurodiversity, including Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD).
- 86 responders were parent carers of CYP who required support related to Speech, Language and Communication Needs (SLCN).
- 184 responders were parent carers of CYP with an EHCP or were undergoing an EHC needs assessment.



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# Section 1: Neurodiverse children and young people



# Responses relating to neurodiverse children and young people (CYP)

- Of 134 responders, we heard a high number of parent carers and their CYP had received support from Autism West Midlands (57), Midlands Partnership University NHS Foundation Trust's (MPUFT) BeeU Service (66), Educational Psychology (52) and Schools (76).
- Responders were less aware of whether their CYP had received support from the following services or initiatives: Autism Education Trust Training (4), Early Bird Team (5), Kooth (2), Preparation for Adulthood Navigators (4) and Rising to the challenge (9).
- 40% (55) of responders reported they had a good understanding of the support available for their CYP. However, only 15% (20) of the responders felt their CYP had been able to access the support available.
- 13% (18) of responders reported they received the support they needed, with 20% (27) neither agreeing nor disagreeing with this statement.
- 16% (21) of responders reported that the support they received whilst waiting for a diagnostic appointment for ASD and ADHD helped, 16% (21) of responders neither agreed nor disagreed.
- Parent carers told us what care and support they thought other parent carers with CYP going through a diagnostic pathway would benefit from to help meet the needs of their CYP and family. We received 111 responses to this question, with a wide variety of comments. These responses have been themed in the following section.



**You said, we did, next steps**



# Ensure clarity about the support available

**You said: Ensure clarity about the support available.** Many parent carers wanted to know more detail of the support available including the possible benefits of the support. It was important to some parent carers that support could be accessed without needing a diagnosis, and families were keen to speak to people rather than being signposted to websites. There was an overwhelming sentiment that more support was needed.

Many parent carers commented on the type of enhanced and additional support they thought would be helpful. This included: post diagnosis counselling support; having a professional lead for each child to work across agencies to lead co-ordination of care and support; services reaching in and more face to face support; more support during the diagnosis; pre-diagnosis support; options to access support for life skills, social skills and self-awareness; access to day time respite and Holiday Activity and Food (HAF) vouchers; more speech, language and communication support; support for sensory needs; access to play therapists, SEN play groups, family support workers and early help; a focus on neuro-affirming approaches; more SEN schools; more support from psychologists and counsellors; activities available for SEN in Oswestry; and more support in Ludlow.

**We did:** The Neurodiversity workstream has collated information about the support available for neurodivergent children, young people and their families. This can be found on the [Healthier Together website](#). Both the 0–5 Child Development Centre and 5–18 BeeU diagnostic service have put additional resource into having practitioners available by phone for those waiting for diagnosis.

**Next steps:** We are continuing to enhance the support available. Updates will be shared through the [Shropshire SEND Newsletter](#).



# Ensure good quality support for early years and educational settings

**You said:** Ensure good quality support for early years and educational settings. Many parent carers felt that teachers needed more training on ASD, ADHD and neurodiversity. Some parent carers specifically mentioned better understanding of how co-morbidities interact. Parent carers specifically referred to wanting schools to listen more and acknowledge their concerns about their children.

**We did:** Additional funding has been put into courses available to schools, such as Autism Education Training to support them in supporting neurodivergent (ND) CYP. Further to this we have three new ND Practitioners who started in January 2024 to support Key Stage 2 and 3 in targeted schools.

**Next steps:** As part of the Partnership for Inclusion of Neurodiversity in Schools (PINS) project, from the 2024 Spring term, children will start to be supported by the new ND practitioners who are working in certain Shropshire schools. For the Summer Term 2024 and next academic year, discussions are underway about the roll out of another initiative to support schools to meet the needs of ND CYP. Further information about the Partnership for Inclusion of Neurodiversity in Schools (PINS) project will be shared in due course.





# Ensure good quality support for parent carers

**You said: Ensure good quality support for parent carers.** Many responders reported they thought better support for parent carers was necessary. A number of people referred to the necessity for emotional support and in some cases counselling. Again, parent carers mentioned the importance of empathy and being listened to. Responders recognised the positive support they had received from the following organisations: Oswestry SEN parent group; PACC including Buddies; SENDIASS and Autism West Midlands. One responder relayed they had offered to set up a support group in a mainstream school, but this offer had not been taken up, and another responder recommended an ADHD support group in Shropshire where you can seek advice and shared experiences.

**We did:** We have put information about national counselling support [from Scope](#) on the Healthier Together website. PACC in conjunction with BeeU have delivered a workshop for social care staff to support their understanding of the needs of neurodivergent CYP and their families. Additionally, the [‘Understanding your child’](#) course is available to all families. We recognise that further work needs to be done to provide support to parent carers.

**Next steps:** In the 2024 Summer term and next academic year, Shropshire will see the roll out the Partnership for Inclusion of Neurodiversity in Schools (PINS) project which will have a role to support parent carers of children in certain schools.



# Ensure referrers know how to make good referrals which are accepted

**You said:** Ensure referrers know how to make good referrals which are accepted. Many parent carers said there needs to be better clarity about how to access the diagnostic assessment services, as they felt they had struggled to get referrals accepted. A few parent carers mentioned that it was problematic that only schools can make referrals and that health cannot.

**We did:** BeeU has shared guidance with schools and GPs about how to make a good referral for the ASD and ADHD diagnostic pathway, setting out the importance of the referrer stating how they see the CYP function, which can be why schools referring is preferable to GPs. The rate of referrals accepted by BeeU for the diagnostic assessments has increased. The [Child Development Centres website](#) has been redesigned in co-production with parent carers to detail helpful information about [the diagnostic pathway](#).

**Next steps:** Work is ongoing in this area, particularly in relation to adult ADHD services.



# Ensure communication from 5 – 18 diagnostic service is clear

**You said:** Ensure communication from 5–18 diagnostic service is clear. Many parent carers said they would have appreciated better communication from the diagnostic services whilst they waited. Suggestions included periodically receiving a letter confirming that they were on the waiting list, how long they were likely to wait, and how they can access other support. One responder suggested: “Even if it’s no news but ‘you are still on the list letter’ that would be preferable to hearing nothing for months/years”.

**We did:** BeeU has started to send out additional letters for CYP waiting on the diagnostic pathway. A new Assistant Psychologist has started in post to proactively reach out to families who are waiting the longest on the diagnostic pathway and provide support to these families.

**Next steps:** The service are developing their processes to respond to referrers and families more quickly after referral.



# Avoid CYP going into crisis whilst waiting for diagnosis by implementing robust approaches to manage risk

**You said:** Avoid CYP going into crisis whilst waiting for diagnosis by implementing robust approaches to manage risk. One responder spoke about their child needing to go into crisis before their referral was accepted.

**We did:** Since the SEND reinspection in November 2022, BeeU has changed its process to review all referrals at a multi-disciplinary team discussion. This enables CYP to access the most appropriate service from them within BeeU, depending on their needs. For those on waiting lists, the BeeU service urges referrers and families to contact their service if a CYP's circumstances have changed and their needs have escalated.

**Next steps:** We will continue to promote that the BeeU service should be contacted if a CYP's circumstances have changed.



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# Ensure capacity of the diagnostic service meets the demands of the population

**You said:** Ensure capacity of the diagnostic service meets the demands of the population. Almost all parent carers who responded commented that the diagnostic process took too long due to the waiting times. Because of this, some parent carers funded assessments privately and recommended this approach. 5 responders spoke about the ASD diagnosis being a ‘true MDT approach’ which was helpful.

**We did:** Since November 2022, additional funding has been put into the diagnostic assessment pathway. This has resulted in additional Autism diagnostic assessments being provided by Healios.

**Next steps:** The health commissioner is in discussion with health provider services about the demand and capacity of diagnostic services to support planning for the 2024/2025 financial year and beyond.



# **Section 2: Children and young people with Speech, Language and Communication Needs**



# Responses relating to CYP with Speech, Language and Communication Needs

- Of 80 responders we heard that a high number of parent carers and their CYP had received support from Educational Psychology (22), Educational Setting and Nursery (27), Schools (39) and Shropshire Community Health NHS Trust Speech Language Therapy (SLT) (30)
- Responders were less aware of whether their CYP had received support from the following services or initiatives: Early Talk (3); Elklan Training (1); IASS (4); Local Offer (0); PACC (3); School Readiness Leaflet (0); Shropshire Community Health NHS Trust SLT Advice Line (4); ShropComm SLT Facebook page (4); SLUK Parent Carer Guides (2); Stoke Speaks Out (1); Talk Boost (3); and Talk Boost Parent Hub (0).
- 44% (23) of responders reported they had a good understanding of the support available for their CYP. 27% (23) of the responders felt their CYP had been able to access the support available.
- 25% (21) responders reported they received the support they needed, with 9% (7) neither agreeing or disagreeing with this statement.
- 26% (21) of responders reported the support they received whilst waiting to see a Speech and Language Therapist helped. 14% (11) of responders neither agreed nor disagreed.
- We also asked parent carers for any other comments relating to their experiences. There were 53 responses to this. These responses have been themed in the following section.



**You said, we did, next steps**





# Ensure clarity about the support available

**You said: Ensure clarity about the support available.** The majority of responses focused on support received from Speech and Language Therapy (SLT) services solely. Very few responses referenced effective support from parties other than SLT. There was a sense that if CYP didn't meet the criteria for SLT, or they were discharged, there was no other support available. Some parent carers commented they were left to fend for themselves with no proper guidance. Others commented that schools felt their CYP needed input from SLT but the SLT service had discharged the child. There were comments about the value of the Severe Speech and Language Impaired Children's Team, but reflection that it only covers KS1.

**We did:** Shropshire Community Health NHS Trust (SCHT) SLT service has developed [a SLT Handbook](#) for parent carers and partners. This details the clinical offer from the SLT service. Across Shropshire, we acknowledge that Speech, Language and Communications Needs (SLCN) is everyone's business, and everyone has a role to play in supporting SLCN. We have rolled out the Talk Boost approach in primary schools and early years settings across Shropshire. The [SLT facebook](#) page is also a helpful resource for advice.

**Next steps:** Work is underway to map the offer of support for SLCN. This will be similar to the information on the Neurodiversity page of the Healthier Together website.



# Ensure good quality support for Early Years and Educational Settings

**You said:** **Ensure good quality support for Early Years and Educational Settings.** Many parent carers commented that schools or early years settings did not follow the advice of SLT, some citing a lack of school capacity to follow the advice. One responder commented that schools need training to recognise behaviour is communication.

**We did:** The Shropshire Community Health NHS Trust SLT service has developed [training sessions](#), some of which are now available online to be accessed at any time. Evaluation of the Talk Boost programme indicates that its role out has been an effective way of schools and early years settings supporting CYP's speech, language and communication needs.

**Next steps:** Sessions on speech, language and communication needs are scheduled with schools and early years Special Education Needs Co-ordinators and Senior Leadership for the Spring term. We are working towards further supporting early years and education settings to meet the needs of children with speech, language and communication difficulties, with plans currently being developed for next academic year. We have received additional funding from NHSE and DFE through the [SEND Change Programme](#) to pilot Early Language Support for Every Child. We will use these funds to provide support to the school and early years setting workforce and build on the Talk Boost approach.



# Ensure good quality support for parent carers

**You said: Ensure good quality support for parent carers.** A number of responses referenced parent carers feeling in the dark and unclear of the support available. In some cases, this was due to therapy taking place in school and not having regular updates from school or SLT. One responder commented that they feel like they can't get support from SLT despite asking the school or GP. A few responders also commented that they could not see the impact of SLT.

**We did:** The [speech and language therapy advice line](#) has been maintained. This is an opportunity for parent carers to contact the SLT service and speak to a trained SLT for advice and tips. Parent carers and schools can access this service without the child being referred to SLT.

**Next steps:** We are working closely with PACC parent carer forum to move forward with support for parent carers. The Early Language Support for Every Child will provide some additional support to parent carers.



# Ensure the capacity of the SLT service meets the demands of the population


**You said:** Ensure the capacity of the SLT service meets the demands of the population. 20% of those who responded commented that they had to wait too long for SLT input, with one parent carer commenting that there was no support whilst they waited. 5 responders commented that they had to receive support from independent SLT, although for some of these cases it was funded by the Local Authority. Many parent carers commented on the good quality service that they received from SLT and named particular SLTs and the SLICC team.

Responses to the survey highlighted that some families have experienced a higher level of SLT input in other Local Areas. We know there is significant variation in what is offered from SLT across the country. Many of those who responded commented that there was a lack of SLT support, with some responders stating that training on its own is not adequate. 5 responders commented that there was not enough SLT support for those with profound communication needs.

**We did:** There has been some reduction in waiting times for CYP accessing the speech and language therapy service, with CYP waiting to be seen through specialist clinical pathways being seen most quickly. Discussions are ongoing between health and the local authority about commissioning speech and language therapy differently. Updates on this will be shared as soon as possible. We are also reviewing the process around funding Augmentative and Alternative Communication devices to streamline this.

**Next steps:** Discussions regarding commissioning of the SLT service are ongoing. Work will continue to enhance the whole offer of support for Speech, Language and Communication Needs.





# **Section 3: Children and young people with an EHCP or going through the EHCP process**



# Responses relating to CYP with an EHCP or going through the EHCP process

- Of 184 responders in total, just over half of parent carers, 53%, (97) felt, when the Education, Health and Care Needs Assessment (EHCNA) or annual review was requested, their CYP's wishes and aspirations for the future were recorded and captured in the application. 45% (81) felt professionals accurately reflected their CYP's needs in their reports and 46% (83) felt listened to and included by the professionals involved in their CYP's assessment/review.
- During the EHCNA/review process, 44% (80) felt their CYP was included and well supported at their educational setting.
- When they received their CYP's Education, Health and Care Plan (EHCP), 50% (91) felt their CYP's wishes and aspirations for the future were reflected in the plan, 58% (105) felt that it accurately described their child and 47% (85) felt that the EHCP meets their CYP's special educational needs.
- 44% (79) of EHCPs or Amended Plans were reported delivered on time, within the expected timeframe.
- Of those parent carers whose CYP already has an EHCP, 66% (122) reported that their child had an annual review in the past 12 months.
- We asked parent carers to comment on the application and assessment/review process and on the plan they received. These responses have been themed in the following section.



**You said, we did, next steps**



# Ensure that the SEN Team communicates with parent carers at every stage in the process

**You said:** Ensure that the SEN Team communicates with parent carers at every stage in the process. Nine responders reported a lack of communication from the SEN Team meant they did not feel informed about the progress of their application. This was especially a concern when timescales were not going to be met.

**We did:** We have increased the number of routine calls we are making and introduced more regular contacts throughout the SEN Process. We have attended parent drop-in sessions hosted by Early Help. This has been well received. The SEN Admin team have introduced a rota to ensure timely communication at every stage.

**Next steps:** We have developed an online portal for annual reviews, which has been rolled out to the majority of our schools. We are exploring the use of digital platforms where progress can be followed by parent carers to support communication. Updates on this work will be shared through the [Shropshire SEND Newsletter](#). We are also piloting and testing digitalisation of the EHCP through the SEND Change Programme [SEND Change Programme](#)





# Ensure that everything possible is done to keep to statutory timescales

**You said:** Ensure that everything possible is done to keep to statutory timescales. Nine parent carers indicated that they experienced delays to processes and some did not know when to expect the EHCP. Five parent carers felt that it took too long for school placements to be finalised.

**We did:** We have introduced a new senior case officer role with responsibility to oversee timeliness and quality. Extra staff have been deployed and all processes are being examined to identify where they can be more efficient to help reduce the currently high workload. We are introducing automation of some processes where possible. We take part in monthly meetings with the DfE SEND Advisor to examine how we can improve our processes, learning from other regions and sharing best practice. We have introduced internal timeliness monitoring meetings.

**Next steps:** There are medium term plans to automate the processes further and, in the longer term, to introduce a digital EHCP process. As part of the DfE Change Programme, Shropshire are implementing an advisory tailored list of schools to support a timely placement process. We expect that advisory tailored lists will improve experiences of the placement process by illustrating choice for families, ensuring placements are suitably matched for the needs of the CYP, and supporting us to strategically manage our placements and provision. [SEND Change Programme](#)



# Ensure that EHCPs meet our child's needs and are of good quality

**You said:** Ensure that EHCPs meet our child's needs and are of good quality. Eight parent carers said that the EHCP missed key information, did not appear to reflect their CYP's aspirations, appeared to have stock phrases or simply did not meet their CYP's needs.

**We did:** We have introduced stringent quality assurance processes to ensure that all EHC plans meet the quality that is expected and reflect the voice and aspirations of CYP. We have developed a new quality assurance framework that has been peer reviewed by an outstanding Local Authority and checked by an Ofsted Inspector. Multi-agency working groups have been established looking at all our process and forms. All our partners who provide advice for EHCPs now use templates that have been reviewed to ensure quality and consistency of advice.

Each agency undertakes a Quality Assurance (QA) check of its own advice reports and what we learn from audits is shared. All new and amended EHCPs are checked and rated by Senior Case Officers and a Multiagency QA team check one in five plans and share learning from these checks with our Quality Assurance Group and back to the team to improve EHCPs.

**Next steps:** We are embedding our QA throughout the panel processes.



# Ensure that settings meet the needs of children and young people as specified on their EHCP

- **You said:** Ensure that settings meet the needs of children and young people as specified on their EHCP. A number of parent carers (23) indicated that schools did not meet the needs of their CYP once they had an EHCP.
- **We did:** We have delivered a set of inclusion events to share knowledge and best practice throughout the sector. These have been supported by senior educational psychologists and health specialists. We have developed a framework of Ordinary Available Provision which sets out the setting-based interventions and support that our mainstream settings should be able to provide for CYP developing a defined offering from settings called the Shropshire Ordinarily Available Provision (SOAP) to provide clarity on the level of support expected from settings. Some schools are engaging in SEN reviews and our regular SENCo network meetings help to support the role of SEND Co-ordinators in schools, colleges and other settings.
- **Next steps:** We continue to embed and develop the SOAP framework within schools and settings and continue to offer support through SENCO networks and Inclusion events. We are taking part in the DfE Change Programme and we have developed our Local Area Inclusion Plan (LAIP) [SEND Change Programme](#)



# Ensure that Annual Reviews happen on time

**You said: Ensure that Annual Reviews happen on time.** A substantial number (19) of respondents commented that their CYP's EHCP had not been updated and no longer reflected the needs of their CYP.

**We did:** We have reviewed the information around Annual Reviews on the [Shropshire Local Offer](#). We have extended the use of an online portal for schools and other settings to submit Annual Review and supporting documentation. We have enhanced capacity of SEN team to respond to amending EHCPs.

**Next steps:** We have identified Annual Review timeliness as a priority moving forward. We continue to examine and streamline processes around Annual Reviews to reduce or eliminate delays in each part of the process.



# Ensure that social care needs are sufficiently included in the EHCP

**You said:** Ensure that social care needs are sufficiently included in the EHCP. Seven parent carers indicated that there was not enough Social Care support or that their CYP's EHCP did not consider health and social care needs sufficiently.

**We did:** A new Care Questionnaire has been developed and introduced in February 2024 which will be completed as part of all new requests for EHC Needs Assessments. This has been co-produced with parent carers. It acknowledges the care needs of CYP and any existing support they have from their family, local community and services. In addition, it will identify any unmet or unassessed care needs and inform the offer of help and support. This is to ensure a holistic picture of the CYP. We improved the training offer to Social Care Practitioners. All new workers coming into Children's Social Care and Targeted Early Help have an induction session with the Designated Social Care Officer (DSCO) or Early Help SEND Operational Lead. A rolling programme of monthly induction sessions are scheduled with the DSCO and includes an overview of role and responsibility of Social Care Practitioners in EHC assessment and planning. A monthly rolling programme of mandatory EHCP training is in place for Social Care Practitioners. By January 2024, 30% of the Social Care workforce and 90% of the Targeted Early Help workforce had completed the training. The DSCO and EH SEND Operational Lead also offer all Social Care Practitioners who are asked to complete Social Care advice to contribute to an EHC Needs Assessment, a one-to-one consultation to support and improve the quality of advice provided.

The DSCO and EH SEND Operational Lead are part of weekly quality assurance activities to ensure Social Care advice is fully representative of the CYP. The DSCO also carries out quarterly audits of Social Care advice to inform future training and workforce development and support the improvement cycle.



# Ensure that social care needs are sufficiently included in the EHCP – continued

**Next steps:** The DSCO and EH SEND Operational Lead have developed an EHCP Annual Review report template for Social Care practitioners to ensure the CYP's current needs, any progress against outcomes and/or changes to Social Care provision are included in the Annual Review process so that the EHCP can be kept up-to-date and reflective of the CYP as they grow and develop. Guidance has also been developed to support the practitioner to focus their report. This is in draft format currently with the aim being for it to be introduced in practice from March 2024. Training will be amended to include the EHCP Annual Review and reporting process.

Ongoing quality assurance and audit activity of Social Care advice for EHCP's, the learning of which will feed into training and workforce development and inform the development of further process guidance. Further work on the advice templates and EHCP template is planned through the SEND Change Programme [SEND Change Programme](#)



# Ensure that preparing for adulthood is prioritised

**You said:** Ensure that preparing for adulthood is prioritised. Three responders felt that the Preparing for Adulthood (PfA) processes did not meet the needs of their CYP.

**We did:** The SEND Area Partnership recognised that the PfA process required review. Responding to feedback, the Partnership has established a PfA Workstream that is ensuring that a thorough review of pathways and processes from Year 9 and to ensure that PfA is embedded from early years. The [SEND Local Offer](#) has a wealth of information and support. We have further developed and improved our supported internship (employability) offer.

**Next steps:** The PfA workstream will be working to prioritise areas for review. Priority 1 will be to examine the PfA and transition processes from Year 9 and onwards. Priority 2 will be PfA from early years. Currently the workstream is mapping out the Year 9 process for CYP with EHCPs. We will continue to increase the offer for supported internships.



Further information about steps taken to address Shropshire's SEND Accelerated Progress Plan can be found here [app-6-month-review-november-2023.pdf \(shropshire.gov.uk\)](#)