In April 2024-March 2025

You Said... We did...

We reported regularly at the Local Authority and Health's strategic meetings to ensure that senior officers were aware of your concerns and could consider opportunities to address them. These are the issues raised in our Annual Survey.

You said… that the Statutory Assessment Team continues to cause worries in terms of poor communication, timescales not being met and lack of knowledge of local schools and services from caseworkers. We…

- *offered our parent carer voice to improve letters that parent carers receive.*
- *worked closely with the Statutory Assessment Team to ask them to improve their communication about waiting times for assessments.*
- *held termly meetings, joined by SENDIASS, to raise issues and proffer potential solutions, including co producing FAQs and letters with Educational Psychology and SAT.*
- *Regularly discussed the need for better communications with the Local Authority*
- *Continue to attend the Local Authorities EHCP improvement plan steering group to make parent carer voice heard within this forum*
- *Working in partnership with the LA to be sure the SEND information hub is providing basic information so that parent carers do not have to phone SAT to obtain this. Information is readily available.*
- *Continue to urge the LA and health to provide more, earlier, better for children and young people with SEND in Cambridgeshire which will be more cost effective by meeting needs sooner in the hope that this may prevent children and young people from ever needing high needs support.*
- *Continue to offer termly education participation sessions for professionals and parent carers to network and discuss issues in the system openly together.*
- *Ensured the voice of parent carers was heard within the area SEND inspection in this area so that the inspection team could be clear that this was a known issue.*
- *Raised the issue regularly with the Local Authority when they were making decisions about their priority areas in the new Inclusion for All strategy.*

You said… that health services are reported to be difficult to access with little to no support whilst waiting, and parents feel they are abandoned once their child is diagnosed. We…

- *continually updated our website to help you find the health information you need for health and mental service services.*

- *continued to promote out Neuro Diversity booklet for parent carers to help them find services and support if they think their child may be neuro diverse. We continue to encourage professionals to use this booklet themselves as well as to share it with families that they meet.*
- *Secured funding for hard copies of our Neurodiversity Book to be kept in central locations such as schools and libraries so that parent carers and professionals can use this as a resource.*
- *Purchased printed copies of our Neurodiversity book that parent carers can purchase from us if they would like to rather than using the free online version.*
- *introduced more health information sessions, with topics selected from continuous feedback from parent carers.*
- *worked with the County's SEND information hub to provide health information through their website.*
- *Continued to offer and improve termly meetings (health and mental health) where you can meet health professionals and talk to them directly (no appointment or diagnosis needed) for help and signposting. These sessions enable parent carers to give feedback on their experiences and thoughts directly to those who commission or work in the services they use.*
- *Include a regular cohort of health professionals who are committed to attending our health participation events to help to develop their services.*
- *raised your voices at the boards we attend and followed up with individuals as and when needed.*
- *worked with the voluntary sector alliance to produce a quality assurance tool to improve health services*
- *regularly attend the ICB participation summit to raise your voices*
- *enabled coproduction on the Keep Your Head website to ensure that parent carers and their SEND children and young people have their needs reflected within the website.*
- *co producing with health and the local authority to produce a package of support for families whilst they are waiting for diagnosis*
- *provided Mental Capacity Act training for parent carers*
- *continue to work closely with the Health Alliance to ensure they continue to have influence over local health services*
- *are working on developing a Cambridgeshire pathway for Neuro-diversity assessments for children and young people*
- *invite 3rd sector colleagues to attend our participation sessions to keep you informed about what else is available.*
- *Have worked closely with health and encouraged them to collaborate with education and social care around the All Age Autism Strategy.*
- *Have worked closely with health and encouraged them to collaborate with education and social care around the All Age Learning Disability strategy.*
- *Have worked closely with dental health services to provide information about why the service is so difficult for SEND children and young people to access. They have taken that feedback and are working on making improvements to the service and also delivered an information session to parent carers about practical strategies that can help.*

You said… the thresholds for mental health services are too high, and the waits are too long. This exacerbates poor school attendance for those who can't attend due to poor mental health. We…

- *have enhanced the information on our website to offer more signposting and support*

- *consistently raised the need for a 'waiting well' offer to ensure we support families, children and young people who are waiting for services.*
- *urged the LA to review its data to understand poor attendance or absence better and use this to inform services that could offer more support to children, young people and their families.*
- *heard your concerns with those who commission and provide mental health services and consistently fed back issues we have heard that reflect parent carer and service user experience.*
- *continued to offer and develop termly meetings, which are mental health specific. At these, you can meet health professionals and talk to them directly (no appointment or diagnosis needed) for help and signposting. These sessions enable parent carers to give feedback on their experiences and thoughts directly to those who commission or work in the services they use.*
- *raised your voices at the boards we attend and followed up with individuals as and when needed.*
- *ensured Younited are regularly attending our participation sessions to hear parent carer voices and they are responding to the issues raised*
- *provided regular sessions for parent carers from our partner organisation Nessie around mental health for SEND children and mental health for parent carers*
- *continued to focus a lot of our sessions on the needs of SEND children with poor mental health and ways to help them such as ADHD and mental health, situational mutism, autism and mental health.*
- *worked with Ed Psychs to co-produce guidance for families around EBSA.*
- *have ensured that Younited are regularly attending our mental health termly participation sessions to hear parent carer voices and they are responding to issues raised. The Younited service manager took away parent carer feedback and as a direct result of these sessions, young people and parent carers can now make self referrals to the service.*
- *Pinpoint champions worked directly with the Mental Health team to develop the Keep Your Head website and provide clearer information for SEND parent carers.*
- *Worked closely with integrated neighbourhood teams across the county to see how the system can work smarter to deliver place based services that are holistic in meeting the needs of children, young people and their families.*
- *Based the topics for our regular weekly information sessions on the things that parent carers tell us are most difficult to get you the information that you need in a timely way.*

You said... emotionally based school avoidance is exacerbated by poor access to mental health services. We...

- *co-produced with NHS Occupational Therapy to help them to develop a model for specialists and mainstream primary schools to make sensory circuits more effective and adapt classroom environments so that children are 'ready to learn'. There should be less triggers to encounter as well as regulation breaks throughout the day.*
- *Continue to co-produce the Ready to Learn Occupational Therapy service to incorporate a model of the service that can be used in secondary schools and early years settings.*
- *work closely with the community nursing team and the learning disability nursing teams.*
- *are developing our relationships with the Integrated Neighbourhood teams to support the development of services within local communities and to raise awareness of the needs of SEND children and young people and their families among universal health care services.*
- *are working alongside the lead Educational Psychologist to develop a Parent Guide to helping your child.*
- *are offering regular sessions to co-produce support for families.*

- *continue to challenge the LA, Health and the DfE to address the increasing issue of school attendance for those who cannot attend (as opposed to those who will not attend).*
- *Worked closely with the LA and Health to co-design and project manage the PINS (Partnership for Inclusivity of Neurodiveristy in Schools) programme and have worked closely in schools to deliver workshops for parent carers and encouraging schools to hear directly from their parent carers and work more collaboratively with them.*
- *Developed and delivered a training programme to school staff teams who were included in the PINS programme about the parent carer perspective - this is now ready to be rolled out more widely to schools.*
- *Are working closely with the Education Access and Inclusion team to think about the LA's alternative provision strategy and how this can be used more proactively to support children and young people in the early stages of EBSA.*

You said… there is a lack of services post-16. We…

- *supported colleagues to offer a dedicated Preparing for Adulthood conference where you could access information and services to find out what is available, as in some cases the services are available but not widely known.*
- *worked closely with the Local Authority to produce a Preparing for Adulthood conference so that parent carers know what is available and to provide their feedback about the offer. We then hosted a parent follow up session to close the feedback loop*
- *have enhanced the information on our website to offer more signposting and support on the Preparing for Adulthood Pages and on the health pages.*
- *evolved termly meetings, which are Preparing for Adulthood (PfA) specific. At these, you can meet health professionals and talk to them directly (no appointment or diagnosis needed) for help and signposting. These sessions enable parent carers to give feedback on their experiences and thoughts directly to those who commission or work in the services they use.*
- *raised your voices at the boards we attend and followed up with individuals as and when needed.*
- *provided additional Pinpoint staff hours to support the development of the new PfA Strategy*
- *raised your voices at the PfA meetings where commissioners and service providers come together around the themes of employment and training.*
- *consistently raised your concerns about post-16 education provision – availability, quality, accessibility, funding, and continuity of courses. consistently requested that services consider social and employment options for those older than 16 who may be NEET (not in employment or education.*
- *worked with commissioners to influence the LA's All Age Carers Strategy to seek to offer more support to those whose children are 16 years and older.*
- *continue to find opportunities for those services that support families whose children are over 25 years old (e.g. Caring Together, who have this contract) and Adult Social Care within the LA.*
- *are working on updating a PfA parents guide to make sure that all of the information is in one place and accessible*
- *are working on a parent to parent guide for PfA*
- *have influenced a post 16 section of the Ordinarily Available Provision section on CCC website*
- *have invited the PfA lead for CCC to attend every participation session with us to hear from parents what the issues they face are and to embed PfA into all areas of work*
- *support the local authority to strengthen their communication with parent carers about what is available*

- *have created a programme of workshops to support you which includes: Preparing for Adulthood Plan in Mainstream Secondary Schools, Banks, Wills, Money, Capacity to manage finances, and Being responsible for own Health post 16years.*
- *are working with the LA to ensure the Local Offer SEND Hub has video clips to explain the things you need know about.*
- *Have worked closely with the LA and Health to steer the direction of the preparing for Adulthood work including work around what is available post 16 and how people find out about it, what happens when and EHCP comes to an end when a young person turns 25, and what is available in terms of day opportunities for young people who require a social care offer at the age of 25 when their school provision ends.*
- *Worked closely with health around the ease of access to Continuing Health Care assessments and the quality of these.*
- *Have ad a presence at school moving on events to raise awareness of the offers of support that are available.*
- *Are working closely with the Speak Out council to try to incorporate a wider cohort of SEND young people's voices in the system.*
- *have requested that the Preparing for Adulthood lead at Cambridgeshire County Council holds her coffee morning sessions in mainstream schools to help raise the voices of young people with SEND in mainstream schools.*
- *are working closely with Cambridgeshire County Council to support them to include a wide range of parent carer voices in the new Preparing for Adulthood and Post 16 strategy they are writing.*
- *are holding parent carer information sessions around 'when our child's needs grow in secondary school' as so many children with SEND seem to 'cope' in primary but SEND needs arise in secondary as a result of overwhelm and the high expectations of independence.*

You said… that you feel professionals lack training, knowledge and understanding. This is particularly the case in schools where the biggest concerns are around a lack of understanding of the needs of SEND children, masking and being considered 'fine in school' and a lack of awareness around school-based trauma and absence. We…

- *are working closely with education partners to develop training and information for schools around these specific issues*
- *are in contact with education and public health officers who are working on this issue to ensure that parent carer voice is heard within the work they are doing*
- *are delivering to Heads, Governors etc re: neurodiversity with LA and health • attend SENCo briefings to provide parent carer voice*
- *continue to feed this concern back at every opportunity within the education system in Cambridgeshire.*
- *Worked closely with the LA and Health to co-design and project manage the PINS (Partnership for Inclusivity of Neurodiveristy in Schools) programme and have worked closely in schools to deliver workshops for parent carers and encouraging schools to hear directly from their parent carers and work more collaboratively with them.*
- *Developed and delivered a training programme to school staff teams who were included in the PINS programme about the parent carer perspective - this is now ready to be rolled out more widely to schools.*
- *Invite a range of professionals to our monthly thematic participation sessions where they have the opportunity to hear directly from parents and carers but also to network with other*

professionals where they regularly feedback that they learn a lot.

You said… there remains an issue around compliance with the law (SEND) and a lack of accountability in schools. We…

- *insisted that this remains a priority for the LA as it moves into the next SEND Strategy Action Plan phase.*
- *raised parent carer concerns with the LA these were shared with Pinpoint*
- *asked the LA to review its tribunal cases to consider whether there were missed opportunities, including around compliance and accountability*
- *continue to raise parent carers concerns around the belief that academies are not able to be held to account with the LA and the Department for Education.*
- *continue to provide legal information and signposting to parent carers on our website.*
- *continue to raise your concerns with the LA regarding school attendance and exclusions*
- *have commissioned information sessions for parent carers around what they need to know about SEND processes in law from reasonable adjustments to statutory assessments to Emotionally Based School Avoidance to neurodiversity in schools.*

You said… that you know the demand for services is high, but the system is complex, and everything is a constant battle with the onus being on parent carers. We…

- *continually review the content of our information sessions and adjust them to cover the topics you say are difficult to find help for.*
- *have updated our website content to reflect the feedback from parent carers and provide the signposting and support you need*
- *continue to provide weekly lunchtime Tii Hubs for peer support and signposting. These sessions also aim to build confidence and empower parent carers to feel able to advocate for their children and navigate the system.*
- *offered a face-to-face conference with education, social care and health services in attendance to offer bespoke advice, information, training and signposting: they were on hand to listen to your feedback.*
- *are working with the local authority to ask for FAQ's from different teams to be on the local offer*
- *hold regular networking and participation sessions where parent carers have the opportunity to feedback their concerns directly to the local authority and health*
- *Worked closely with the LA and Health to co-design and project manage the PINS (Partnership for Inclusivity of Neurodiveristy in Schools) programme and have worked closely in schools to deliver workshops for parent carers and encouraging schools to hear directly from their parent carers and work more collaboratively with them.*
- *Developed and delivered a training programme to school staff teams who were included in the PINS programme about the parent carer perspective - this is now ready to be rolled out more widely to schools.*
- *Suggested that the LA brings together a collaborative from across the system to think about what positive changes can be made system wide and now have a regular attendance at this group to ensure that parent carer voice is raised.*
- *Undertook Autism Education Trust training as a whole team so that we can help parent carers to understand what training is offered to school staff and try to keep everyone working consistently.*

You said... there is a lack of joined up thinking and working across services meaning that parent carers have to tell their story multiple times and they have to chase a number of services simultaneously. We...

- *Continue to encourage services to work in a joined up way and to attend our termly participation sessions to hear directly from parent carers about what can help.*
- *Worked closely with integrated neighbourhood teams across the county to see how the system can work smarter to deliver place based services that are holistic in meeting the needs of children, young people and their families.*

You said... there is not enough support at an early stage so families end up in crisis before support is offered. We...

- *develop our information sessions based on YOUR feedback.*
- *continue to add to our website based on the questions you ask*
- *promote the latest information and sessions through our monthly newsletter and through our social media channels*
- *ask partners (Education, social care and health) and schools to tell parent carers about the support we offer*
- *ask at each Pinpoint session what topics you would like to have and plan our timetable to this. review our feedback each month to inform how we deliver further support, information and signposting .*
- *will do our very best to continue to design our programme around what you ask for - by parents for parents!*
- *Have raised parent carer voice in the rewrite of the Joint Statement of Needs Assessment to ask that the needs of children and young people with SEND and parent carers are recognised centrally within this strategy.*
- *Have asked the educational psychologists if they have any material that could be made available to parent carers about trauma informed models of practice.*
- *Undertook training with the University of Warwick to be able to deliver Coping with Unexpected Everyday Situations training to parent carers and this has been offered to parent carers in seondary schools.*
- *Based the topics for our regular weekly information sessions on the things that parent carers tell us are most difficult to get you the information that you need in a timely way.*

You said... there is not enough easily accessible information. The SEND information hub (Local Offer) is not well known about and is difficult to navigate. We...

- *Continue to meet regularly with officers responsible for the SEND information hub to provide your feedback to them and try to suggest ways that it could be made easier to navigate and better publicised.*
- *have termly meetings, joined by SENDIASS, to raise issues and proffer potential solutions, including co producing FAQs and letters with Educational Psychology and SAT.*
- *Based the topics for our regular weekly information sessions on the things that parent carers tell us are most difficult to get you the information that you need in a timely way.*

You said… you can feel overwhelmed with caring responsibilities, and this gives you the time and energy for little else – it can also weigh heavily on your own mental health and well-being.

We…

- *are working closely with the Local Authority to embed parent carer voice into the All Age Carers strategy*
- *continue to provide a nonjudgmental safe space for parent carers to get support and information*
- *provide regular parent carer sessions to increase the confidence of parent carers – you are the expert*
- *provide regular sessions for parent carers from our partner organisation Nessie around mental health for SEND children and mental health for parent carers*
- *increased our offer of in person Tii hubs that provide parent carers with a safe, nonjudgmental space to meet others who ‘get it’ and to get support and signposting*
- *continue to offer regular twilight sessions and lunchtime day time sessions to allow parents who work to have more opportunities to be able to participate.*
- *held our annual in person conference to allow parent carers to see the range of support and information that is available and to provide system feedback.*
- *have undergone training to be able to deliver the University of Exeter Healthy Parent Programme for our parent carers.*
- *Are working on a series of short videos to be available on our website around how parent carers can support their own wellbeing as well as that of their children and young people.*
- *Have worked closely with the NSPCC on producing materials for children, young people and their families about how to stay safe online.*
- *have a team that is made up of those with lived experience of being part of a SEND family and who are mostly parent carers themselves. We ‘get it’, we know how difficult it is and that it is not our child’s fault. This is why we continually and tirelessly raise our voices together at every opportunity so that parent carers needs are recognised, validated and supported. You are not alone.*