

In 2023 - 2024

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 able to consider opportunities to address them.

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.*
- *have termly meetings, joined by SENDIASS, to raise issues and proffer potential solutions, including co producing FAQs.*
- *welcomed the Sat Team reorganising on the back of feedback and a review of how to improve the service.*
- *welcomed the SAT Team, introducing a new case management system intended to reduce delays, improve workflows and enhance communication. This also enables the Local Authority (LA) to review data on the service and seek continuous improvement.*
- *fed back the concerns over identifying schools suitable for potential placements: the SAT team introduced a new panel process to improve place allocation. We suggested that they make the school place offer easier for parent carers to understand by providing transparent information which sets out all special schools available in Cambridgeshire, their specialisms, and place availability to enable parent carers to understand the reasons behind the choice they are offered (this doesn't restrict parent carers from offering up their own preferences from outside of the list).*
- *Regularly discussed the need for better communications with the Local Authority influencing their decision to buy a new case management system, CACI, which should be implemented before the end of 2023 allowing communications to improve*
- *Worked with the Local Authority to produce a policy that gives clear guidance to parent carers about children being educated outside of their chronological age group.*
- *Secured a seat on the Local Authorities EHCP improvement plan steering group to make parent carer voices 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.*
- *Presented the parent carer perspective to the SEND 0-25 service at their away day*

You said... that health services are reported to be difficult to access, and parents feel they are abandoned once their child is diagnosed. We...

- *updated our website to help you find the health information you need for health and mental service services.*
- *created and launched a Neuro Diversity booklet for parent carers to help them find services and support if they think their child may be neuro diverse.*
- *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.*
- *introduced 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.*
- *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*

- *consistently raised the need for a 'waiting well' offer to ensure we support families, children and young people who are waiting for services.*
- *consistently raised the issue that parents feel abandoned post-diagnosis. We are delighted that Health has begun a Neuro-diversity pathway review and are including Pinpoint in the steering group. The work will pick up offers of support pre-, post and without a diagnosis.*
- *asked the LA to review their 'parenting courses' to make the offer feel more like support and less like a judgment on parenting skills. We updated our website to provide parent carers with signposting and to set out why a diagnosis for ADHD requires an evidence-based approach in line with the NICE guidance and, therefore, why parent carers are offered a course to enable the evidence to be gathered. We challenged professionals to rethink how the evidence could be gathered in other ways as part of the new Neuro-diversity-pathway work.*
- *have used some of our resources to enhance the information offered for parent carers through our free on line sessions.*
- *invited specialist nurse for the community paediatrics team to every health participation session to ensure that parent carer voice is heard*
- *added additional sessions as need is identified and gaps in specialist information become clear e.g. epilepsy and dentistry*
- *worked with Occupational Therapy to help them to develop a 'ready to learn' programme for mainstream primary schools to ensure that sensory circuits are used and helpful for children. They continue to offer phone lines for parent carers and for schools.*
- *worked with specialist health services to influence an ARFID pathway for Cambridgeshire so that children who have Avoidant Restrictive Food Intake Disorder can get the support they require.*
- *worked with public health on their new child weight management procurement process to ensure parent carer voice was heard*
- *worked alongside professionals on the development of a situational mutism pathway. They have changed the name from selective mutism to capture that our young people do not have a choice.*
- *brokered meetings with health and education to address parent desires to have a FASD diagnostic pathway,*
- *are working with health and the local authority to develop a Neuro-developmental pathway or Cambridgeshire*
- *worked with the Integrated Care Board to provide parent carer voice to the Mental health key workers programme who work to prevent mental health in patient admissions for children and young people*
- *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.*
- *identified an issue with wheelchair services and have highlighted it with professionals and they are considering this within the context of their future commissioning.*
- *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*
- *applied to be part of the Voluntary, Community, Social Enterprise Mental Health, Learning Disability and Autism board*
- *continue to work closely with the Health Alliance to ensure they continue to have influence over local health services*

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.*
- *invited the LA to run a dedicated session to hear the voices of parent carers whose children were struggling to attend school*
- *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.*
- *shared 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.*
- *introduced 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*
- *secured Nessie being commissioned by Cambridgeshire on the back of us raising that there is a need for mental health support for children and young people with SEND needs that is delivered in a way that they feel well supported*
- *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.*
- *attended a Younited team meeting to help them understand how best to signpost parent carers*
- *are working with Ed Psychs to co-produce guidance for families around 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.*
- *raised concerns about the closure of education provisions with the LA to understand the LA's powers to require continuation.*
- *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*

You said... that a lack of funding seems to drive a lack of services and SEND support. We...

- *asked the LA to share what it was doing in relation to funding so you could understand the situation and raise your voices.*
- *invited the Director of Schools to speak directly with you on the Safety Valve Funding and funding more generally to hear your questions and concerns first-hand, which he did.*
- *consistently raised concerns about the impact of the savings (30%) required by the Government of the Cambridgeshire and Peterborough Integrated Health Care Service, which commissions local health services, and the risk of impact on children and young people's services.*
- *are co-producing with the LA and health on 'support while you are waiting' for an autism assessment so that you have access to information to support your child*
- *produced a Neuro-diversity booklet that is available to download freely providing Cambridgeshire specific information about support and services for children and young people with any Neuro-diverse need.*
- *are working on developing a Cambridgeshire pathway for Neuro-diversity assessments for children and young people*
- *are co-producing with the LA on their SEND transformation programme to provide more, earlier, better for children and young people with SEND in Cambridgeshire which will be more cost effective by meeting needs sooner with the hope that this may prevent many children and young people from ever needing high needs support. However, those who need higher levels of support will still be able to access it.*
- *invite 3rd sector colleagues to attend our participation sessions to keep you informed about what else is available.*

- *are co producing with NHS Occupational Therapy to help them to develop a model for 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.*
- *invite a member of the mental health teams comes regularly to our mental health and education participation sessions to hear directly from parents and carers and to feed this back to the system to try to put more preventative measures in place and to develop the mental health teams understanding of the different approaches needed by SEND children and young people. They have also developed 'support whilst you are waiting' packages as a result of their work with us.*
- *include a regular cohort of health professionals who are committed to attending our health participation events to help to develop their services.*
- *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.*
- *facilitate the head of school readiness and early years' service is now working with us on termly parent carer sessions to provide information and strategies.*

You said... that parent and child blame continues to cause concern for parent carers who feel that the advice and support at early help stages is aimed at neurotypical children. We...

- *encouraged the Early Help team to share the Pinpoint Neuro Diversity booklet with their staff and those families they support.*
- *have produced a Cambridgeshire specific Neuro-diversity book that is available to download for free*
- *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*

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*
- *provide regular sessions for parent carers from our partner organisation Nessie around mental health for SEND children and mental health for parent carers*
- *secured Nessie were commissioned by Cambridgeshire on the back of us raising that there is a need for mental health support for children and young people with SEND needs that is delivered in a way that they feel well supported*
- *continue to provide weekly peer support Tii hubs that provide parent carers with a safe, non judgmental space to meet others who 'get it' and to get support and signposting*
- *launched 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*

- *launched twilight sessions and moved our regular information sessions to a lunchtime to allow parents who work to have more opportunities to be able to participate*
- *launched a new PMLD (profound and multiple learning disabilities) Tii hub once per month so that parents of children with different needs feel that they also have a space that is designed for them to get the support they need,*
- *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*

You said that children's restrictive diets are a real worry and that you need help with this. We...

- *have worked with specialist health services to influence an ARFID pathway for Cambridgeshire so that children who have Avoidant Restrictive Food Intake Disorder can get the support they require.*
- *co-produced with public health on their new child weight management procurement process to ensure parent carer voice was heard*

You told us that you felt we sometimes didn't offer enough around disability, and you felt we were very Neuro-diversity-focused. We..

- *explained that we have specific funding to offer Autism and Attention Deficit Hyperactivity support, which is why we offer specifically branded sessions. We also explained that the session content might be useful to a wide range of parent carers, including those whose children are Neuro-typical.*
- *are offering an programme of free workshops from Pinpoint*
- *launched a new PMLD (profound and multiple learning disabilities) Tii hub once per month so that parents of children with different needs feel that they also have a space that is designed for them to get the support they need,*
- *updated the website to have more disability specific information*
- *had a wider range of professionals at our participation sessions to talk about specific conditions such as epilepsy*
- *offered free Mental Capacity Act training to parent carers*
- *offered free finance sessions to parent carers via DISH (Disability Huntingdonshire)*
- *hosted a parent feedback session after the local authority PfA conference*
- *regularly attend the Palliative care board to feedback parent carer voice*
- *hold regular sleep information sessions that cover a broad range of additional needs*
- *regularly attend the PfA health board to provide parent carer voice*
- *had wheelchair services attend our annual conference and have also liaised directly with them about an identified issue*
- *invited a wide range of services to attend our annual conference including CamRare, Down Syndrome group and Little Miracles*
- *regularly attend the Learning Disability Partnership Board to raise parent carer voices*
- *asked for Voiceability to feedback to send partnership board from high support needs committee to ensure a wider range of voices are heard in the system*

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*
- *offered to deliver a 'schools' conference on behalf of the LA*
- *continue to feed this concern back at every opportunity within the education system in Cambridgeshire..*
- *Are working closely with health and education to co-produce a new offer for schools to work more closely with parent carers and develop their understanding and practice around neurodiversity (PINS)*

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.*
- *offered (to the LA) that we run a conference similar to the one for parent carers but for schools*
- *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*
- *offered parent carers a session with LA officers to directly raise your concerns with them.*

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*
- *attended the local authority SEND team away day to provide the parent carer voice perspective*
- *hold regular networking and participation sessions where parent carers have the opportunity to feedback their concerns directly to the local authority and health*

You said... Preparing for Adulthood needs more done to make it work for young people and parent carers. We...

- *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.*

You said... really hard to help your children when they are struggling and can't attend school due to their anxiety. We...

- *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).*

You said...you can feel overwhelmed with caring responsibilities We...

- *are undergoing training with University of Exeter to deliver the Healthy Parent Programme for our parent carers from the summer term.*
- *work with Caring Together to signpost to additional sessions and parent carers support*
- *continue to speak up to ask the LA to provide more parent carers assessments.*

You said... its hard to find what you need and the waiting times feel like forever. 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.*
- *know how complicated the system can be, so we delivered a session on Communicating Your Childs' Needs to Professionals last month. You also wanted more around ADHD in school so its in our timetable, along with ADHD and the impact to Mental health.*
- *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!*

