

pinpoint

for parents by parents



SUPPORTING, INFORMING, INVOLVING AND EMPOWERING
CAMBRIDGESHIRE PARENT CARERS

JANET DULLAGHAN

Chairs of Trustees'



As the Chair of the Trustee Board, it gives me great pleasure to introduce this Annual Report. It sets out our work to date, outlining our plans, ambitions, and commitment to working together across Health, Social Care, and Education to support parents and carers of children and young people with SEND. Pinpoint is a Charitable Incorporated Organisation (ICO) governed by a board of trustees. The Board, many of whom are parent carers of children with SEND, shapes the strategic direction of Pinpoint and provides its governance.

At Pinpoint, we focus on engaging and empowering parents, embedding co-production, and ensuring parents can participate in influencing services so all children can achieve their full potential. Much of what we do enables parents and carers to increase their knowledge and understanding of their children's needs and the services and support available in the local area. We help to build parent carers' confidence and resilience through peer-to-peer support, training, access to information and guidance, and signposting to services and support.

For many in the SEND world, it feels like things are getting harder - services are struggling, and waiting lists are getting longer. Against this background of increasing difficulty, the work we do takes on even greater significance and importance. When parent carers feel alone and cut off by the system, they need more support than ever.

This has been a challenging year. With the changes within Cambridgeshire and Peterborough Local Authority (LA), many roles have changed, and the NHS reconfigurations, including the replacement of the Cambridgeshire and Peterborough Clinical Commissioning Group with the Integrated Care Board, have been challenging. Both the LA and the NHS have continued to fund Pinpoint, valuing the co-production work we do with them, and in spite of these challenges, Pinpoint has consistently delivered against families' priorities.

Over the last 5 years, Pinpoint has grown into a stronger, more stable and more effective organisation. It has continued to provide high-quality services to fulfil its contracts and grants through information, involvement, support and training for parents and carers, parent groups, service providers and commissioners, providing strong parent carer voices and further embedding the co-production process across all services and support.

With a small, dedicated, and hard-working team of eight part-time staff, a Trustee Board of seven, and parent carer 'Pinpoint Champion' volunteers, Pinpoint facilitates strong parent-carer voices, which have resulted in numerous improvements to services over the years, as evidenced in this and our previous Annual Reviews on the Pinpoint website.

The new Strategic Plan 2023-2028 details Pinpoint's considerable achievements over the last 5 years and the challenges going forward. We have set out in this Strategic Plan our ambitious developmental Goals for the next 5 years, seeking to deliver the best possible outcomes for all children and young people with additional needs in Cambridgeshire. Pinpoint's Strategic Plan 2023-2028 can be downloaded from our website: <https://www.pinpoint-cambs.org.uk/about-us/strategic-plan/>

Janet

HELLOS & GOODBYES

We said goodbye to Fay Dutton and Christine Stocker Gibson after many years of long and dedicated service to Pinpoint. Both had led Pinpoint seeing us from our first beginnings around a kitchen table to the organisation we are today. They have seen us through a variety of challenges and we genuinely would not still be here were it not for their dedication and passion to all that we do. Thank you Fay and Christine for all your support.

Janet Dullaghan joined the Board of Trustees last year and is our new Chair of Trustees. She now leads us into another chapter as we seek to bring to life the new Strategic Plan. She is joined by two new trustees: Sarah Gusscott and Sue Berry. Sarah is an Occupational Therapist by profession and Sue is a marketing professional. They bring their professional expertise and personal desire to make a difference for our children and young people to their new roles. They are joined by Kerry Swannell who has been offering her professional accounting expertise to our Finance Sub Group. We are also joined by two new staff members. Sara Basuc is a former County Council colleague who we worked with us on the Opportunities Area work and we are delighted she has joined us to deliver the new Neuro Diversity Booklet and our new training offer. She is joined by Amy Wyles to support us in our Communication activity. Amy's background in private client law brings welcome strength to our team. Betty Tzeng, a Clinical Psychiatrist joined us for six months to learn more about what we do. We want to continue to expand and strengthen the board and welcome the opportunity to speak with anyone who may be interested. We particularly want to hear from parent carers with children and young people in education. We acknowledge that time is precious, and we can be flexible in the demands we make of trustees.



Janet
Dullaghan



Betty
Tzeng



Sue
Berry



Sarah
Gusscott



Kerry
Swannell



Sara
Basuc



Amy
Wyles

Our year in numbers

Pinpoint has had another busy year working with parent carers on our participation work to help improve Cambridgeshire services for families with children and young people with SEND (Special Educational Needs and Disabilities).

5351

Social media
followers

3901

Parent carers attended
Tii Hubs, workshops
and groups

169

Strategic meetings
with parent carers
represented

Workshops
& Tii Hubs

123

151

participation
opportunities

162,773

webpage
views

21

Pinpoint
Champions

Meet our Team

Pinpoint is a Charitable Incorporated Organisation governed by a board of trustees. The Board, many of whom are parent carers of children with SEND, shapes the strategic direction of Pinpoint, provides its governance assurance, and oversees the Chief Executive Officer. They work hand in hand with the staff team, who are also parent carers, to make the strategic aims into operational activity. The staff, in turn, listen to parent carers and shape Pinpoint's offer accordingly, in line with the funding we receive.

Trustees are volunteers and meet once or twice a month to fulfill their roles. Our staff team are all part-time and term-time only, with the exception of the CEO who is part-time year-round. The staff team all have specific roles but are multi-skilled able to cover multiple operational functions, as needed in such a small team.

Our Trustees



Janet Dullaghan
Chair of Trustees



Tina McKewan
Treasurer



Hasan Amjad
Trustee



Dawn Hall
Trustee



Sarah Guscott
Trustee

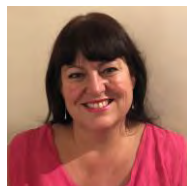


Kerry Swannell
Co-optee



Sue Berry
Trustee

Our Staff



Sarah Conboy
CEO



Lisa Belton
Deputy CEO



Linda Green
Engagement and
Participation
Officer



Bianca Cotterill
Finance Officer



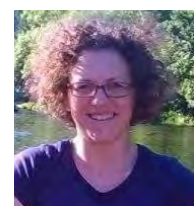
Michelle Quail
Communications
Officer



Karina Whittington
Session Host



Amy Wyles
Deputy
Communications
Officer



Sara Basuc
Engagement and
Training Officer

OUR CORE BUSINESS



We are the DfE Parent Carer Forum for Cambridgeshire and part of the regional and National Network of Parent Carer Forums

As Cambridgeshire's Forum, we are also a member of the Eastern Region Parent Carer Forum (ERPCF) and active members of the regional SEND Network.

We attended a two-day virtual National Network of Parent Carer Forum (NNPCF) Conference and a face-to-face NNPCF Conference. We have taken part in training throughout the year. Our contribution was recognised by both the Secretary of State and School Ministers.

We have worked with Department for Education Colleagues to ensure voices from our region have been heard directly by those delivering national policy and practice.

The ERPCF commissioned Forums to undertake new Health work, such is the strength of our network.

Sarah, our CEO, is a representative for the ERPCF working regionally and nationally on behalf of parent carers, as well as Chair of the regional forum. Lisa, our Deputy CEO has just become a regional and national representative too.



Local Authority and Health Parent Participation and Co-production

The ongoing challenges post-pandemic with a cost of living crisis have continued to have a lasting impact on families, their children and young people. We have continued to be a vital communication channel to get information out to parent carers. We had a dedicated part of our website where we provide information to support parent carers on cost of living. We have continued to raise the issues that families face.

The pandemic delayed many of the commissioning and policy changes that had been anticipated. This has been exacerbated by the separation of Peterborough and Cambridgeshire Local Authorities, and their staff. We have taken every opportunity to ensure parent carers are participating in service development and co-producing new services and SEND policies.

We continue to deliver a range of workshops and training funded by the Cambridgeshire and Peterborough Integrated Care System (ICS). These include Attention Deficit and Hyperactivity Disorder (ADHD)/Autism Spectrum Disorder (ASD) groups, Expert Parent training and Challenging Behaviour workshops. The ASD/ADHD groups continue to run each month online. We have been able to provide a wide range of speakers offering advice and support on topics parents tell us they need. This year these have included mental health, anxiety, behaviour management and managing sleep.

SEND Peer Review

The Local Authority and Health invited peers from other authorities to look at Cambridgeshire and give their views on areas for improvement. We enabled parent carers to contribute to this important piece of work.



PROJECT UPDATES

In 2023-24 we actively sought additional funding, which led to several new projects.



Pinpoint Champions

We have continued to support and slowly grown our current cohort of Champions. They are a small but powerful team able to advocate for parent carers, signpost to services and offer peer support. They feedback on services and help us at sessions with service providers.

Pinpoint Tii Hubs

These virtual groups had been running since 2022. We offer a two hour drop-in each week in term-time. These sessions offer parent carers a safe space to seek help and support, be signposted to services and to recognise that they are not alone. The Monday sessions are open to all parent carers. We have tried offering sessions specifically for families of children with Profound and Multiple Difficulties as the needs of this group of parent carers are often more specific as they are further through their SEND journeys earlier than many who join us at Tii Hubs. We looking again at new ways to reach this group of parent carers.

Pinpoint Workshops

We started these with funding from the Opportunities Area. They have proved so important to parent carers that we have funded these with the help of the County Council going forward. The programme responds to the issues parent carers raise with us and covers a wide range of topics for families with children and young people of all age groups and with a wide range of needs. These sessions are integral to our participation offer, providing direct feedback through the surveys we do and through the comments made during the workshops. We have also moved the sessions to span lunch-hours seeking to accommodate those parent carers who work but can join us in their break.

Twilight Sessions

These have come about from the ongoing request from parent carers keen to join us but unable to do so in working hours or when their younger children are awake. When we piloted these previously we struggled to get good take-up but we have been delighted, if not a little overwhelmed, by the number of parent carers joining us on a Wednesday of Thursday evening. This year these are funded by Huntingdon Freeman. We will continue to provide this offer whilst we have the funding and parent carers available to host.

WHAT PARENT CARERS TELL US:

"It's helpful being an evening session."

"I found this very helpful most professionals just tell you to get on with it or don't understand."

"It was good to hear that we are already doing some of the right things and also get new ideas. Also nice to hear that we arent alone."

"Understanding my son's needs more and how to help him.."

PROJECT UPDATES

In 2023-24 we actively sought additional funding, which led to several new projects.

pinpoint
Champions

pinpoint
Tiihubs



Huntingdon Freeman's
Trust



Location-based offer - Huntingdon

We have been running a location-based project in Huntingdon over the last three years, thanks to funding from Huntingdon Freeman. The project was to make a direct offer to schools to identify and train Pinpoint Champions who could support parent carers associated with each of the pilot schools. With each year we have evolved the project to reflect the need of parent carers, and schools. This year we have moved the Tii Hubs to an off-site satellite model based at the Maple Centre in Oxmoor. We have been able to support 42 parent carers through this initiative and through the provision of location-specific information on our website.

Neurodiversity Booklet

We first discovered the Essex Forum/ Essex partners and NHS commissioned last year and asked if it might be possible to have a version created for Cambridgeshire. We were delighted when our ICS was able to broker an arrangement with Essex to provide the template and then to fund us to create a Cambridgeshire version that we could share with parent carers. The booklet had a soft launch in September and has been viewed by 4810 parent carers, reaching 30% of our parent carer audience. We have developed training to offer alongside it and have rolled it out to parents, schools and professionals.

WHAT PARENT CARERS SAY ABOUT THE BOOKLET:

"I have been researching all summer trying to get it clear in my head how the EHCP process works if looking at special schools etc and couldn't get my head round it – you literally explained it in a sentence! (Though not expecting it to be as easy as it sounds!!) I have no doubt it is going to make a HUGE difference to so many families, thank you so much ."

"As usual, lots of useful information and valuable real-life experience, as well as emotional support."

"Amazing to have a guide through every step filled with processes, tips, and general information in a really easy to read and dip in and out of format! "

"Makes me feel more confident about how to move forward and how to support my child. Also will help me explain to my husband why she needs different support to other children as he thinks it all just behavioral "

"Practical and created by those who know and have lived experience."

Comentary On The Year

It would be fair to say that for those of us who have been on the SEND journey for some time it feels like it is getting harder - services are struggling, waiting lists are stretching out, and it feels like the system is designed to say no! Those who are starting their journey will have no comparisons. Those who had hoped the 2014 reforms would bring welcome support and inclusion for their children are now looking at a future of adult care with no real tangible support.

This all sounds bleak for a team of parent carers who remain resolutely optimistic. But this outlook is the only way we can stay energised and focused on making the system and experiences for families better. The SEND system is struggling for resources and from the overwhelming tsunami of need post-pandemic. We have watched the Local Authority and Health fight for more resources and valiantly seek to transform SEND in Cambridgeshire. But resilience is low for professionals (and parent carers) and it's a daily battle. As a Forum, we can only help parent carers if we stay positively and constructively engaged with the system. This frustrates those who are angry about a failing system and want us to campaign, but our Forum status prevents us from doing so –our Forum status prevents us from doing this. So we do all we can to provide searingly honest feedback, remembering that those who have to commission and deliver services often feel as frustrated as those of us who use the services.

Against this background of increasing difficulty, the work we do takes on even greater significance and importance. When parent carers feel alone and cut off by the system, they need more support than ever.

The isolation they feel (and their children feel) is harmful, and we are playing our part to provide a safe place where they can find peer support; it has never been more needed. As the system becomes harder to navigate and feels like there are more barriers, providing timely, free information with practical support enables those waiting for services to have the knowledge they need to support their children. Empowering parent carers with knowledge and skills enables them to stand up and ask for what's needed and fight for it if required. Giving parent carers the confidence to know they are doing all the right things helps them to stay positive and better able to support their children. Providing an inclusive Forum where it's okay to say it's awful and yet also to say when things are going really well is vital. The challenge for us is helping families to understand that every day we are playing our part to make things better for their children. Our You Said, We Did is a snapshot of the activity we undertake to make that difference. You would be forgiven for thinking that Pinpoint is a huge organisation with endless resources – we are eight part-time parent carers with lived experience and a budget that barely breaks even. And yet, the tone of this report speaks to our can-do attitude and determination to be here for the next 15 years.



Our new 5-year strategic plan 2023-28

We set ourselves a hugely ambitious task as we started 2023 - business as usual, our three core priorities (extending our reach and empowering parent carers, promoting co-production and influencing policy and practice) whilst embarking on a new business plan to deliver financial independence and sustainability.

Our team of eight part-time staff all have individual roles and responsibilities but all have to be able to cover for each other to ensure we have business resilience. We are all always pushing the boundaries of our knowledge and developing our skills and this year has been no different. We have needed to expand our technology skills as we have continued to explore how our digital presence can enable us to reach more parent carers - we've been using artificial intelligence to game the ever-changing social media algorithms!

1. Extend reach & engagement, & empowering parents

- Review Reach and Engagement Strategy (including our communications methods) by March 2023 and reset for the year ahead.
- Communicate our Pinpoint Forum Handbook (with a focus on coproduction understanding) with LA as we experience staff changes
- Develop a communications funding income stream proposal by July 2023
- Develop a new proposal for face-to-face Tii Hubs Offer using Champions in schools by July 2023
- Bring on stream (if approved by the Board) a new face-to-face Tii Hubs Offer using Champions in schools by July 2024
- Develop a proposal for a new face-to-face Champions in key settlements programme by March 2023. Bring on stream (if approved by the Board) a new face-to-face Champions in key settlements programme from September 2023.
- Develop an independent income stream proposal to ensure that all Tii Hubs are care businesses by July 2023.
- Carry out a rolling review to ensure that Pinpoint's signposting materials (website and Handy Guides) are up to date by March 2024.
- Develop a Pinpoint Supporter Programme proposal by July 2023 and seek funding in 2023-2024.
- Develop and train Pinpoint Champions, growing the cohort incrementally to broaden reach across Cambridgeshire, to retain a cohort of around 30 Champions by March 2024.
- Develop a new membership offer by July 2023.

Business Plan 2023-24



The new Neurodiversity Booklet is 280 pages that was researched, rewritten and then formatted before being published and promoted online. We further developed training modules to share with parent carers and professionals.

We spent considerable energy on our influencing and relationship management in the face of considerable staff changes in health, social care and education. This stretched our capacity when we then supported the Local Authorities Peer Review, Their Transformation Programme, and Health's new Neuro-Development Pathway.

2. Promote Co-production

- Work with the LA to refresh the LA's Coproduction Toolkit to ensure it reflects the Cambridgeshire SEND Strategy and Cambridgeshire SEND Pledge commitments to coproduction and remain aligned with national SEND good practice guidance from July
- Work with the LA to ensure its day-to-day working reflects the Cambridgeshire, and Peterborough SEND Strategy and Cambridgeshire and Peterborough SEND Pledge commitments to coproduction and remain aligned with national SEND good practice guidance throughout 2023-2024.
- Proactively work with the LA and Health to ensure that they understand and embed coproduction to every opportunity - through one-to-one relationships and meetings, formal LA and Health Boards, relationships with commissioners (including grant monitoring) and structures, and by including coproduction feedback in reporting to Boards, throughout 2023-2024.
- Develop a self-funding coproduction training programme proposal for schools and professionals by July 2023.
- Develop a coproduction training proposal for parent carers by July 2023.
- Seek funding (subject to Board approval) for the parent carer training proposal by March 2024.

3. Influencing policy and practice within Cambridgeshire and beyond

- Identify (and maintain) the key relationships from April 2023.
- Identify and secure seats around the LA and Health policy tables from April 2023.
- Train staff to utilize feedback and soft intelligence in reporting and dialogue with LA and Health partners by July 2023.
- Identify what service improvements are needed and wanted through monthly data and soft intelligence reviews to inform reporting to LA and Health partners from April 2023.
- Pinpoint's monthly newsletter will include updates on Pinpoint's influence on policy and service improvements from April 2023.
- Pinpoint's 'You Said, We Did' will be published six monthly on our website - September and March.
- Pinpoint Communications will promote Pinpoint's 'You said, we did' through social media - September / October and March/April.
- Develop and then utilise monthly reporting to ensure that those attending key LA and Health meetings have the information they need to reflect key messages and make use of soft intelligence and feedback by September 2023

ASD/ADHD Information and Support Offer ICS

Deliver three sessions monthly - from March 2023

Business Plan 2023-24

Core Information and Support Project CCC

Deliver three sessions monthly - from March 2023
Introduce new twilight offer from June 2023

Neuro Diversity Project ICS

Develop a project plan by July 2023
Deliver from September 2023
Develop training offer to support the project by July 2023
Deliver training offer from September 2023

4. Ensuring Pinpoint is fit for the future while remaining financially sustainable

- Produce and agree on a financial strategy by September 2023.
- Produce and agree to detailed business/project proposals which produce additional income for Pinpoint from March 2023 onwards.
- Identify and agree on new income streams for unrestricted funding, including donations from March 2023. Review in September 2023.
- Identify and agree on project proposals for restricted funding from March 2023. Review in September 2023.
- Ensure negotiations around grant (Health) continuation happen in good time from September 2023.

Business As Usual

Monthly reporting to Board - policy, strategy via CEO Report
Monthly Finance Reporting to Finance Sub Committee
Monthly reporting to senior LA/Health Boards
Monthly newsletter
Day to Day comms
Contingency Planning
HR and line management
Trustee Governance
Contract Management and Reporting
Board Support
Policy Updates
Infrastructure procurement and management
Licenses and Insurances



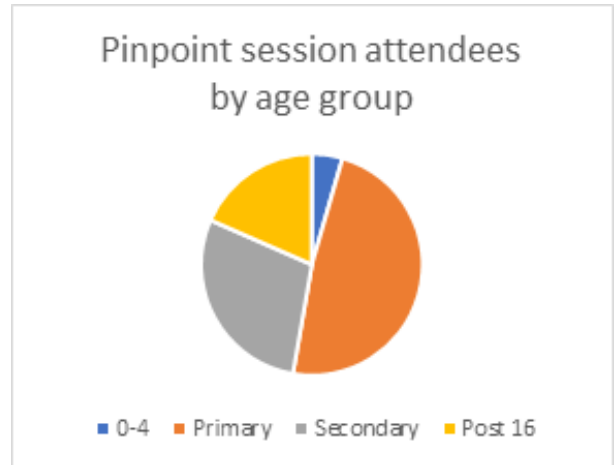
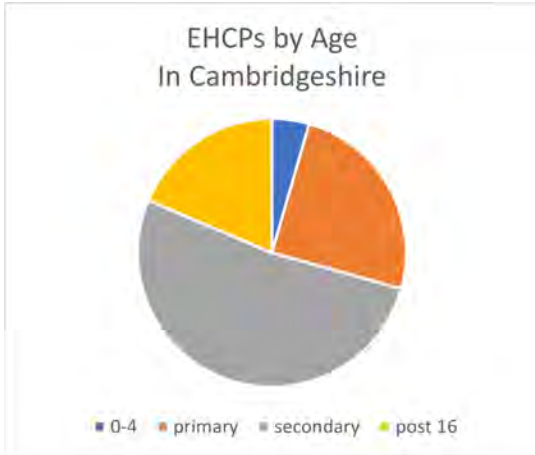
We worked to ensure that we strengthened our participation offer with new termly meetings with health, mental health, social care and education. This new approach enables parent carers to participate more frequently and professionals to easily engage in all aspects of their policy and delivery development. The new Forum Participation Group has helped us to hear the voices of those who don't engage directly with Pinpoint but are known to other local organisations.

We looked at our own internal skills and gained both a Carers Tick, the Safeguarding Best Practice Award to equip us to better meet parent carers needs, and the Good To Go Quality Mark from Hunts Forum.



Our Aim: Extending our reach to help more parent carers

Empowering parent carers by reaching them early in their SEND journeys is key to the work we do. We hear more from parent carers of primary-age children (SEN Support) than the number who have Education Health and Care Plans in this age group. This meets our aim of empowering parent carers early in their journeys. We work with the Early Help teams (Social care, education) to promote the support we can offer families early in their journeys.



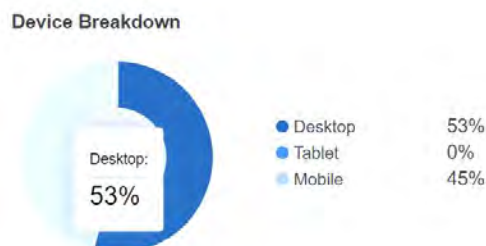
We collect a wide range of data from different sources - virtual sessions where people attend 'in person' and complete surveys and provide feedback for us, and then there is data we collect from our website and social media platforms, generated by the hosts' software. This can give us challenges in interpreting the information - for example the website can tell us gender (of who the account is registered to) but that doesn't necessarily mean that is who used the account. We do know that our website is a source of information for those starting their journeys, with around 173% of those accessing it year after year being new visitors.



New v returning visitors to website 2023-2024

Empowering parent carers through high-quality information and resources via our website. We have refined and relaunched our website to be content-rich and organised to make navigation easier. It now meets Level One Accessibility. The changes we have made makes the website more accessible on mobile devices.

Devices used to access website 2023-2024



WHAT PARENTS SAY ABOUT PINPOINT:

"Thank you ever so much. So great to have found information to support my concerns. Really appreciate this service."

"As always, I have come away from these kind of Sessions from Pinpoint, with even more knowledge about how to help my Child and additional information that I am able to take away to help get her more detailed support."

"Thanks Pinpoint for another great session on something so many children are struggling with."

"As usual it is lovely to talk to other parents who get it and who have been through or are going through similar things - it's a great place to come for advice and support."

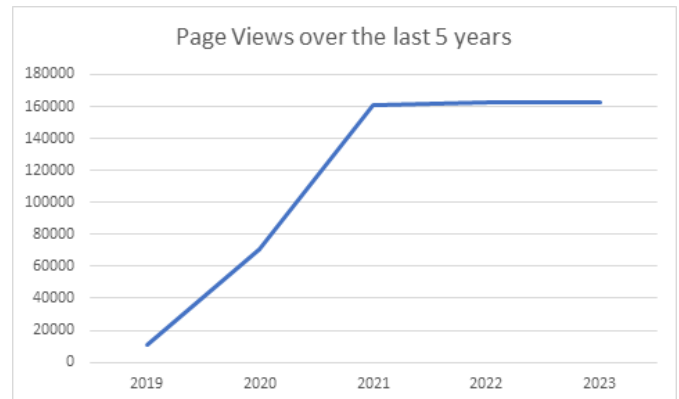
"Very friendly atmosphere."

"Today I had so much invaluable information to help with a current crisis. This is a truly unique resource."

"It was really empowering to hear from other people and to get links to further advice."

"I felt seen and heard and like many other parents were going through or had been through similar experiences. I feel much more confident moving forward with my son."

The number of pages viewed has increased in the last 5 years by 452%. We know that we are reaching more new parent carers consistently year after year.



We recognise that how people reach our website varies but our data shows the importance of our social media channels as a means of directing people towards our information. Of our top ten arrival locations to our website, 63% of our website visitors arrive from Facebook, 11% arrive directly from the Local Authorities Local Offer and 4% arrive having accessed our newsletter.

Empowering parent carers by providing the right information through Pinpoint sessions. 7.5% of those who attend take the time to complete our feedback. 92% of those say they find the sessions very beneficial. 96% feel encouraged to take action as a result of attending our sessions.

Our sessions are commissioned based on the most common needs. Since Covid, Social and Emotional Mental Health has overtaken Autism and ADHD as the largest group of need that parents attending our sessions report. This may include children with or without a diagnosis. We know that more families are reporting children and young people's mental health has become a concern post-pandemic - higher numbers are reporting anxiety and struggles with attending school are common concerns for parent carers. We also know that some children and young people communicate through their behaviour and families continue to report a high incidence of poor, challenging or concerning behaviour, which would also come under the Social and Emotional Mental Health (SEMH) category.

It should be noted that we are funded by the NHS (Cambridgeshire and Peterborough Integrated Care System) to provide monthly Autism and Attention Deficit and Hyperactivity Disorder (ADHD) information sessions. These needs make up the biggest groups of need amongst those who respond to our Annual Survey. Some of these children also have co-occurring conditions - for example, SEMH. This is why we usually enable parent carers to record multiple needs, in any combination, when they report.

PARENTS TELL US:

"Imagine how much could be achieved collectively if our energy was used in a way in which we are all listened to and things changed accordingly for the better! "

"Invaluable information from other parents who really understand because they have been there."

"As well as providing great emotional support, the pinpoint team have great knowledge of the system and can advise on the next steps."

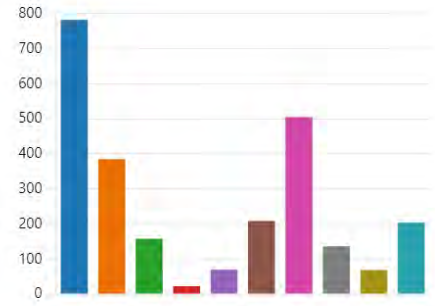
"A really useful session which combined general practical information and advice, discussion, personal experience/anecdotes from the presenters and group discussion and peer support in the chat."

"Very insightful session brilliantly presented by an expert in the field; I particularly liked the practical suggestions which helped me to reflect on my approach, which was really helpful."

"I'm glad I joined this today, got more info from this than I have in the past couple of years! "

"Pinpoint is a valuable support and is doing amazing work to help parents and carers who need them! Well done to all those involved - you are very much appreciated"

"Pinpoint Cambridgeshire everything you do is spot on and so informative and helpful."

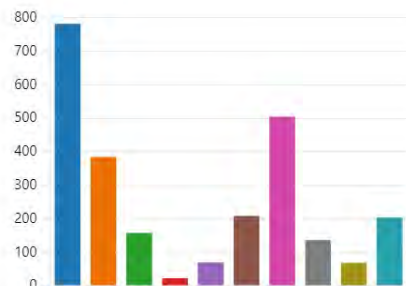


Taken from those completing Our Annual Survey 2023-2024

We use Pinpoint resources to provide information sessions relating to SEMH and specifically to issues such as managing challenging behaviour, improving mental health, supporting children and young people who experience anxiety and how families can help improve sleep patterns. We often provide sessions that cover multiple needs, responding to the likelihood of co-occurring needs.

We have provided 151 opportunities for parent carers to gain information and support in the last 12 months – averaging three Pinpoint information sessions per month and a weekly Tii Hub (peer support session) in term time.

We regularly update our website information and resources in response to parent carer identified needs and signpost via our social media channels. We work with the Local Authority, Health and SENDIASS to ensure they understand changing patterns of demand and proactively seek additional support to match emerging patterns of need.



Percentage of needs identified by the parent carers who complete our feedback surveys at the end of our sessions.

Reaching out to help hear everyone's voice: a strategy to reach out to those we hear from less often and who are often under-represented.

Empowering our parent carers to navigate the system and feel confident to make progress on their own. 92% feel they have the information they need to take the next step (Pinpoint Session Feedback). The quotes throughout this report highlight this.

Empowering our parent carers by building their confidence. 92% say that they appreciate feeling they are not the only ones in their situation (Pinpoint Session Feedback).

Reaching those in "our audience" is a real challenge as not all will know about Pinpoint. We ensure that we do all we can to reach out across the school system, making sure that at least once a term we are included in the Director of Schools' email sent out to all schools and settings – we include text which can be lifted and put straight into communications which schools and settings share with parents.

Our parent carers predominantly access information through social media – we reach 5351 who follow us this way. We are prominent on other organisations' social media as a way of raising our profile and reaching more families who might not know about us or look for us.

We reach out across schools, settings, children's centres, food banks, places of worship, and GP surgeries. We ask our partner organisations to use their networks and we attend events. Our Champions work to reach people in their own communities too.

pinpoint
for parents by parents

Pinpoint Cambs
1,388 followers · 1,384 following

Twitter

<https://twitter.com/pinpointcambs>

pinpoint
for parents by parents

Pinpoint Cambridgeshire
1,388 followers · 1,384 following

Facebook:

www.facebook.com/pinpointcambs



pinpointcambs · Safe Profile · 0

1,388 posts · 372 followers · 37 following

Pinpoint Cambridgeshire
Cambridgeshire Charity helping parent carers with children and young people with additional needs and disabilities.
www.pinpointcambs.org.uk/pinpointcambs/

Instagram: [pinpointcambs](https://www.instagram.com/pinpointcambs)



Our newsletter:

www.pinpoint-cambs.org.uk/news/

Tii HUB ATTENDEES SAY:

"Tii hub is such a lovely supportive and understanding environment- it's great to know at the end of a difficult week that there is a group of people I can talk to who just get it. Thanks pinpoint for everything you do! "

"Having a supportive community who is engaged and generous with their experience and knowledge is priceless. "

" It's good to know we can come to tii hub with our questions and often someone knows the answer or can point us in the right direction of someone who does."

TRUSTEES SAY:

"Volunteering for Pinpoint provides me with a opportunity to give something back to a community that has helped me navigate the SEN world"

"Being trustee allows you to see the amazing work the group does and have an input into findings and make suggestions on future plans."

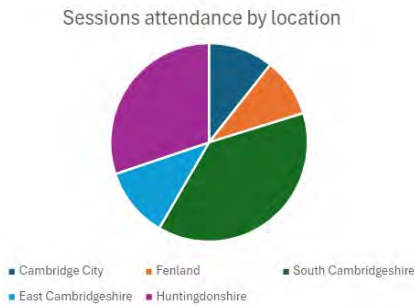
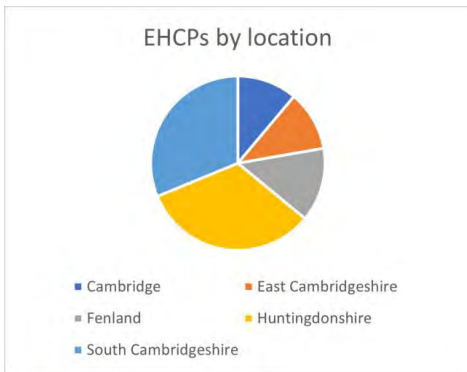
"Being a trustee for Pinpoint allows me to be part of a team of compassionate individuals working collaboratively to support families and champion the best interests of children with additional needs".

"I am really glad to be learning more about SEND in Cambridgeshire and listening to the perspectives of parents and carers."

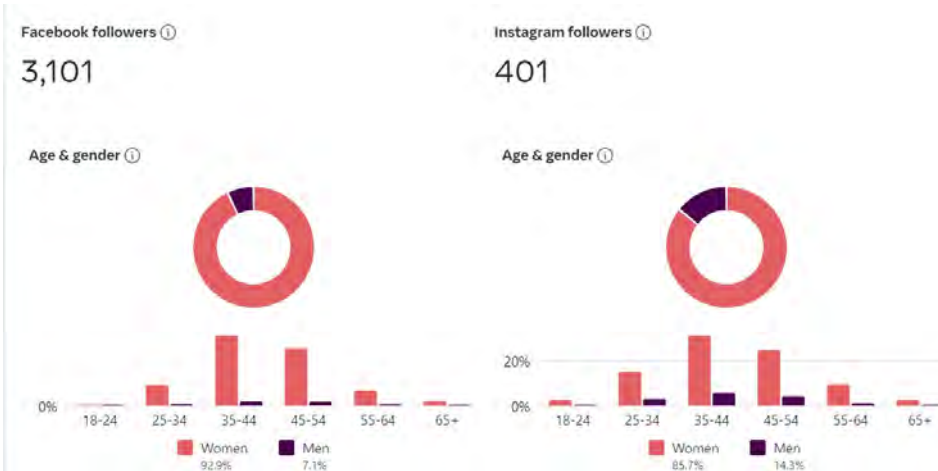
Ethnicity

The families we are reaching match the ethnicity profile that Cambridgeshire has for those with EHCPs. Although the populations are small, we do see families from most ethnic groups living in Cambridgeshire. We work with the Local Authority's Early Help Teams and those who work with Traveller's communities to promote Pinpoint.

Geography The impact of geography is comparable between the percentage from each location known to have EHCPs and the reach we are achieving from our sessions, where known.



Age and Gender As already set out in the limitations of the data paragraph, our social media platforms record the age of those registered with internet providers but it is possible for others to be accessing our website through someone else's account. Based on the hosts' data, the age profile of our audience is predominantly 35 - 54 in age but this varies in how they access Pinpoint.



Our social media audience by age and gender.

CHAMPIONS SAY:

"I want to give something back to an organisation who have done so much for our family."

"I'm a champion because I want to help in anyway that I can, pinpoint helps me and so many others so it's the least I can do!"

"Feeding back for session topics - I said to my husband that there's no better feeling than suggesting a topic for a session and it being really well received."

"It's only a slight exaggeration to say that Pinpoint has been the only helpful support we have had in our SEND journey."

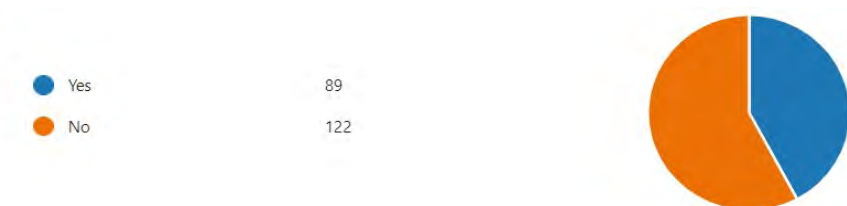
"Being a Pinpoint champion is doing what you can when you can and most of the time it's when your so exhausted from your life but you just HAVE to give back to others."

"I'm a champion because I know how it feels to feel like you are alone in all of this and I don't want anyone else to feel like that."

We try to offer sessions throughout the day and have experimented with a SENDads twilight session when funding allowed. We do get dads joining us in the day, but it is still predominantly mums we see. Now we have resumed our twilight sessions we are seeing more Dads once again. The data that we can gain from our social media and website analytics gives us insight into who accesses through which social media channel. Instagram seems to be proportionately more popular amongst the dads.

New insights about how parent carers feel their children and young people are included in out-of-school activities with their peers.

It is increasingly apparent that many children and young people with SEND feel isolated and need more support to feel included and to participate in social activities.



Does your child / young person feel included in out-of-school activities with their peers?

WHAT PARENT CARERS SAY ABOUT INCLUDING THEIR CHILDREN:

"Better staff or more staff trained in special needs so they feel s like they are burden ."

"Teenagers need to be kinder. It is not a structural thing."

"To just be asked if they would like to be involved rather than just assuming that they don't."

"More inclusive services, where she doesn't get stared at for being different."

"Invited to do stuff with others 'Play days with others."

"Availability of bespoke interest focussed small group activities especially mid-week."

"We have no afterschool provision."

"To have safe places to go and have fun and meet people who understand and get her. People who are in her "tribe"."

WORKSHOP ATTENDEES SAY:

"Very validated and understood, knowledge about sleep has improved, was able to connect with other parents in a similar situation to me."

"This presentation gave me a much better understanding of my daughters issues and how to deal with them. I've read a lot of stuff but this concise presentation was completely on point. The experiences of the other parents were very helpful and the book recommendations too."

"The welcoming, open and practical environment is always helpful especially with topics that mean so much."

"This was a really great talk. (The speaker) is really knowledgeable and understanding and her advice is tailored to our children's needs. It's so great to hear professionals that understand that our children need different approaches."

"Keeps me sane(ish) ."

"I am not alone."

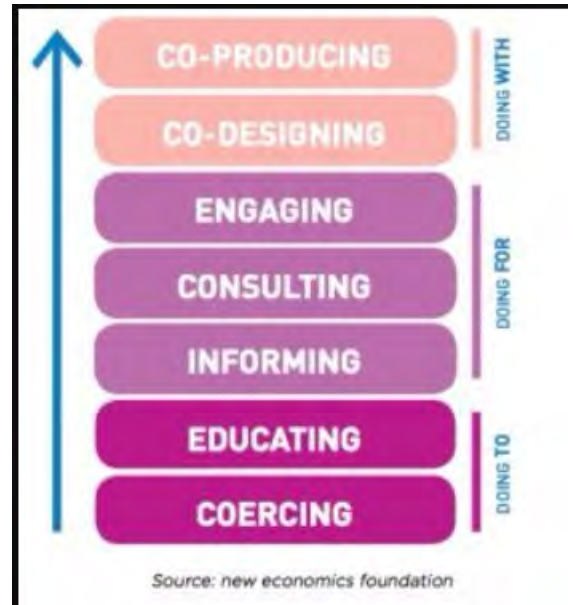
"Delivered the talk well. Easy to listen to. Took away some useful info."

"An absolutely fantastic session. Thank you for giving us parents an opportunity to speak to the professionals ."

Our Aim: Creating opportunities to promote co-production and participation

Co-production provides a process for sharing decision-making power. In collaboration, the principal decision-maker invites others to join them in the process. Collaboration, like consultation, seeks to surface the best ideas through dialogue, exploratory questions, and identifying best practices. In co-production, however, it is the collective participants who determine the best way forward and make the decision together.

Co-production is the way we work with the Local Authority and Health staff. We promote co-production at every opportunity – it is where we all work together as equals with professionals and services, all listening to each other, valuing each others' viewpoints, and doing the best for the child or young person. Good co-production also means working together when implementation takes place, and this is happening in Cambridgeshire through formal structures (boards and working groups) and by working with officers.



Co-production is embedded in the Cambridgeshire and Peterborough SEND Strategy

Cambridgeshire and Peterborough’s SEND Strategy and Pledge restates the commitment to co-production and uses the co-production info graphic to illustrate this.

The Local Authority has reaffirmed that the contribution from Pinpoint in developing the Local Authority’s SEND policies, strategies and commissioned services is highly-valued and respected by the Local Authority, with open, honest and constructive exchanges being a feature of its work as the Parent Carer Forum.

In addition to Pinpoint being an independent Parent Carer Forum, it is also funded by the Local Authority to provide additional capacity for co-production. Parent carers use their lived experience to design, improve and enhance services. Pinpoint assists in the collation of parent carer views on relevant and focused areas of activity in order to co-produce improved policies and services. Pinpoint also provides feedback to enable service commissioners to evaluate the services they commission and to consider how well services meet the needs and aspirations of the children, young people and families for whom they provide.

Participation

We work to ensure parent carers are heard by those who commission (buy) services for Cambridgeshire children and young people – we do this through our Participation Toolkit (see below). We are proactive in seeking out participation opportunities and creating them where possible, but we also facilitate the work of others to get their voices heard by sharing ways to take part. We work to create opportunities for parent carers to bring us their issues and concerns so that we can ensure they are taken back to those making decisions about services. As we are committed to hearing all our parent carer voices, we also have a more detailed Seldom Heard Strategy to ensure that we take every opportunity to engage with all our parent carers.

We facilitate participation on behalf of the LA (education and social care) and Health, on behalf of local SEND organisations (e.g. Cambridge Children's Hospital), on behalf of the NNPCF and we share opportunities to participate in SEND research. The principle system for this is our social media channels.

Tools we use for participation:

Pinpoint's website

Social Media: Facebook, x (formerly Twitter), and Instagram

Pinpoint Reference Forum

Pinpoint Partners in Commissioning

Working Groups

Pinpoint Focus Groups

Meet the AD Network Sessions

Meet the Head of SEN Network Sessions

Network Meetings

Termly Session for Education, Health, Mental

Health and Social Care with LA and Health professionals

The Pinpoint Champions Network Workshops

Commissioning specific tasks and finish groups



Pinpoint Surveys including the Annual Survey

Tii Hubs

Pinpoint's Annual Conference

Pinpoint's monthly newsletters

New Forum Participation Group

WHAT PROFESSIONAL SAY ABOUT US:

"Strong support and professional challenge from our parent carer forum Pinpoint."

"Pinpoint are like your best friend who says you dont look good it that dress" - speaks to how we share honest and challenging feedback."

"Pinpoint regularly challenges us" - what the Director of Schools says about us"

"I am an Education Inclusion Family Advisor working with a family who has a 8yr old diagnosed with ASD who hardly sleeps. I have found this [Pinpoint workshop]very informative and will share with the family."

"I am not a parent of a child with SEND, but I am a professional from a support service where we try to help educational, health and social care professionals better support children's emotional wellbeing. I found it really useful and beneficial to hear about the issue of anxiety and school refusal from a parent's perspective and better understand the challenges parents are facing. Thank you so much for offering this session."

Improving school attendance We know many children can't attend school (rather than won't / choose not to attend). This is a cohort of children and young people with significant needs, in many cases not being met, which causes them to be out of school. We have sought more help for families, children, and young people by raising their voices, which are being heard. The new Alternative Provision Strategy Action Plan is being co-produced, and we continue to make the case that we may need a wider range of settings to support a return to school.

We are improving Education Health Care Plans through co-production. We continue to work with the LA to ensure that EHCPs reflect the needs of parent carers and provide sufficient specificity to be upheld, should it be required. This remains a challenge as the LA see EHCP numbers rapidly increase without the resource to administrate to increase alongside it.

The timeliness of statutory processes remains a practical issue for families and the Statutory Assessment Team. In raising your concerns, the LA continues to review how it is structured to meet timescales and will be trialling a new approach that it hopes will improve timeliness.

Compliance and expectations are the cornerstone of the Local Authorities SEND Strategy priorities, as parents told us it is an ongoing issue and a key priority to be resolved. As a result of us continuing to raise parents' voices, it remains a priority going forward. The LA continue to grapple with the challenges of achieving this in a system devolved to schools, where the LA's powers are limited.

We strive to seek more support to be provided early and more effectively for all children and young people with SEND. The Local Authority has introduced a co-produced resource and supporting guidance to help schools and settings know what support should be made available to children on SEN Support. This is known as 'ordinarily available provision', or OAP.

We have begun co-producing a long awaited new Neurodiversity Pathway that seeks to offer a clear route to diagnosis and support to those who are on the pathway (even if they don't receive a diagnosis). This is still in its early stages and will require more engagement to progress into delivery.

We were delighted to be able to deliver the new Pinpoint 'Supporting Your Neurodiverse Child' booklet. The booklet is now launched, and we are receiving positive reviews from those who have accessed it - we've had in excess of 4,500 downloads. We will be launching co-produced training alongside it.

We are part of the new national PINS (Partnership in Neurodiversity in School) programme alongside the Local Authority and Health. Over 20 schools will pilot a new support package including co-production with parent carers at school level supported by Pinpoint.

"Waiting Well" is a concept we introduced eighteen months ago – it's the principle that if you have to wait to see a specialist, you can manage this better if you are not in crisis and have active support in place whilst waiting. We are pleased that health and education services are using this idea to co-produce a new 'waiting well' offer.

We continue to co-produce the new SEND Information Hub, ensuring that it meets the needs of parent carers. In parallel, we continue to ensure our website evolves as parent carers seek support from us – we respond to topics raised by individual enquirers and themes that emerge from our participation sessions.

We have revisited our co-production focus groups to make them work better for parent carers and offer more opportunities for service commissioners to engage directly in participation and production. We now have four formal network sessions a term on the themes of health, mental health, education and social care.

Pinpoint's Annual Conference. This year we returned to holding a face-to-face Conference. This was a well-received day which saw more than 120 parent carers attending , over thirty stall holders and fifteen workshops. The day provided an opportunity to gather information, hear the latest updates on services, participate in service development and network with others.

Participation in Children's Mental Health and Well-Being Services. Parent carers and professionals co-produced the new Strategy which reflected the feedback Pinpoint facilitated. This has resulted in new services coming 'on stream'.

Participation in the new Integrated Care System through the Children and Maternity Collaborative
We have a seat on each of these and have used this to feedback not only parent carer voices but also to escalate concerns about keeping children out of crisis whilst waiting for services. This has resulted in an enhanced offer for families, children and young people.

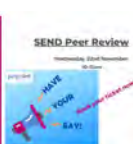
Participation in the National Health Service Key Worker Programme. We continue to work alongside this activity which is intended to keep children and young people from entering mental health inpatient care (if it can be avoided) through better support at home.

Participation in the development of the combined SENDIASS service. We have a seat on the Board to help the service meet the needs and aspirations of families who need independent advice and support in Cambridgeshire.

Participation in Peer Review. The visit in the Autumn Term has enabled parent carers to share their thoughts about how SEN in Cambridgeshire works for their children and what they would want to see in services and support for children and young people.

Participation in Emotionally- Based School Avoidance. We are working alongside a lead Educational Psychologist develop a Parent Guide to helping your child with their emotions that will be co-produced with Pinpoint families.

Participation in Preparing for Adulthood - Helping the LA to develop its parent carers support and add more visuals on the website to better explain what to when, questions to ask in school to make sure your young person has the right support.



CHAMPIONS SAY:

The reason I wanted to be a pinpoint volunteer is because I attended a few pinpoint meetings about children with additional needs and found them very helpful . They made me feel less alone and that other people got how I felt . So I wanted to be able to return the favour and give something back so that other parents never have to feel like they are alone.

The role of being a volunteer has given me a sense of pride that I can help others who may be struggling and to help them feel less alone. It also makes me feel that I belong and that there is always help if you need it .

I would recommend Pinpoint to other parents because if they are struggling and feel alone there is always someone there to help and understand its hard when you have a child especially a child with additional needs it can be daunting and you can feel isolated with Pinpoint there is always someone who gets you it's like a big family."

Why Participation matters to parent carers:

"The impression left by GPs and school that no-one understands or is able to provide support was balanced in the session by hearing from health professionals who have compassion for the plight of parents/carers struggling to get support for their SEND children. One of the participating NHS professionals undertook to investigate possible sources of support saying they would contact me about it later. I hope that the health professionals got the message that simply referring families to school is not necessarily an appropriate or helpful response."

"A useful session to both hear from professionals and share our experiences with them (and of course the usual pinpoint parent community sharing with others who are in a similar situation)."

"Hopeful that communication and speech & language needs can be addressed beyond age 19."

"It was really helpful to speak to Jo and get her advice on how to proceed in getting support from school."

"The health professionals were very informative and covered a wide range of subjects. Linda was excellent in hosting the event and the range of discussion was useful, in terms of identifying other paths and support available to our family and useful to understand other needs that the other carers/parents and children have."

"It cleared up some of the myths school have said to me."

"I realised the futility of the battle."

"I am a new Parent to Pinpoint and I was wholly welcomed from the beginning, I felt so comfortable and all my questions were answered."

Some of the representation undertaken this year:

SEND Comms Group	Forums Participation Group	Hunts Forum CEO Group
Young People and Families Co-production Collaborative	Neuro Diversity Pathway Development Group	Learning Disability and Autism Board
Children and Young People's Mental Health and Well-being Board	East of England Co-production Group	PfA Strategy Steering Group
East Of England SEND Forum	East of England Co-production Group	Neuro Diversity Regional NHS Group
Partners in Commissioning	Carers Programme Board	Children's Hospital Volunteer and Community Sector Forum
Eastern Region Parent Carer Forum	SEND Executive and SEND Partnership Boards	Cambridgeshire SEND Communications Group
SEND Advisory Group	Children, Young People, and Families Co-Production Collaborative	Carer-friendly tick steering group
Children and Young People's Palliative Care Forum		Fentland Charities Network Forum
Early years meetings	Children and Maternity Collaborative	Children and Young People's Mental Health and Well-Being Board
Pre-diagnosis parent groups	Wheelchair Forum	EHCP Improvement Steering Group
SEN Sufficiency Plan	Keyworker Collaborative lessons learned	Children's LD Health Needs Assessments
Healthwatch Health Alliance	Alternative provision coproduction working group	CCC SEND Executive Board
Keep Your Head (Mental health) website redevelopment survey	SEND provision and placement panel	SEND Peer Review
Health Alliance	CCC Transformation Board	All Age Autism Pathway
		Learning Disabilities Pathway

Our Aim: Influencing policy and practice in Cambridgeshire and beyond

Cambridgeshire

Influencing policy and making sure that it reflects parent carer's and their children's, needs and aspirations is crucial in making the biggest difference for Cambridgeshire families: if the policy is right then the practice that comes from it should be right too. This is only possible where policymakers are committed to co-production and where there are robust professional relationships underpinned by trust: some of the conversations we have are difficult and sensitive but they are also fiercely open and honest. Without this, we would not be able to affect change on behalf of our parent carers. We celebrate the positives, look for the 'better if's' and are clear about the gaps, and what simply doesn't work.

We do this by having a seat on each of the strategic policy boards, presenting updates and raising issues, and contributing to every discussion on emerging work in social care, education and health. The expectation is that the information we provide is considered in the round and, wherever possible, is acted upon - to change policy, to influence further investigation or even to disagree with so we can co-produce alternative options.

We work hard to ensure that as many individual parent carers as possible have the opportunity to work directly with policymakers through the participation work we do: hearing directly for those whom the policy impacts upon is incredibly powerful and policymakers regularly refer to the conversations we've facilitated. We work with Health Watch, Fullscope, Hunts Forum, and Caring Together to raise local voices.

Across the region

We are active members of the Eastern Region Parent Carer Forum, using this to raise voices across East Anglia. We routinely participate in the Regional SEND Network meetings, the Preparing for Adulthood Network, the Autism Network, the Neuro-Developmental Disorder Network and the Palliative Care Network. We have been working with the new Children's Hospital. We speak up and aim to not only shape policy but ensure that our parent carers benefit from any new and emerging work intended Cambridgeshire families and children.

National

Parent carer voices must be heard at the highest levels of decision-making and we take every opportunity to make those views heard nationally. We have taken part in discussions around the emerging new Participation Tool that will be used to benchmark local areas in terms of how they engage, co-produce and can show that they listen to parent carers and young people. We take every opportunity to feedback through the National Network of Parent Carer Forums, as well as using our contacts in the Department for Education. We have spoken up over concerns regarding SEND resources and parental concerns that a lack of money and competition for resources could disadvantage their children. We provided feedback on the SEND Green paper and were vocal participants at the NNPCF National Conference. We have raised concerns about the challenges of supporting young people post-18 who may have mental capacity but lack the understanding to make good choices: this is a real worry for many families.



Our Aim: Securing our financial future so we are here for you

We worked hard to build a secure financial position to enable us to have confidence that we can weather the challenges that all charities face in terms of the vagaries of public sector income streams. We have appropriate levels of reserves and sufficient funding to enable us to deliver our core business.



Pinpoint has improved the financial monitoring processes to enable the Trustees Board to have a clear view of the finances and regularly monitor income and expenditure for existing contracts, grants and other funds. We secure Hunts Forum 'Good To Go', which is an independent quality assurance standard for the Huntingdon voluntary sector and confirms our governance is robust.

Additional funds have been raised successfully for discrete projects such as developing parent Champions. We are in year three of a two year grant from the Local Authority to continue to deliver parent participation and engagement services. The Local Authority have confirmed their ongoing commitment with the offer of forward funding. We continue to have a contract with the Cambridgeshire and Peterborough Integrated Care System: the new contract is for two years with an option to extend for a further two years. It enables us to provide ASD/ADHD workshops, which are a lifeline to so many parent carers, offer additional mental health support and contribute to the Key Worker Programme. We were delighted to be supported by Allia and Hunts Forum to access additional business growth training and some bespoke consultancy support.

We are incredibly grateful for the donations and grants we received from our other funders. St Ives Town Council continue to support us with our office accommodation. This year we have also had a grant from Huntingdon Freeman, Tesco, Coop and Cambridgeshire Community Foundation. Supporters have donated through charitable shopping, made online donations and even held bake sales for us - thank you Little Aqua. We have been charity of the year for The Worshipful Company of Launderers and nominated by Peterborough Amazon warehouse staff for a donation.



Planning ahead, we need to raise our own funds from other sources or receive additional funding to carry out specific work such as running face-to-face parent support groups and developing webinars or training packages. To do this we will:

- Identify and secure fundraising opportunities to sustain existing activities, achieve developmental goals, and diversify sources of income.
- Ensure that Pinpoint has the capacity and can act swiftly to harness funding opportunities as they present themselves.
- Develop the Board to support the growth of Pinpoint.



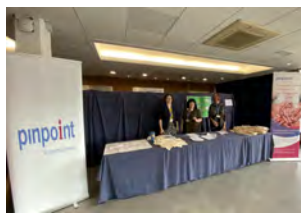
Pinpoint Annual Conference September '23



Moving On event at Spring Common



Pinpoint at the Local Authority's Transformation Conference July '23



The Queen at our Eastern Region Meeting



WHAT PARENT CARERS SAID ABOUT OUR CONFERENCE:

"Really helpful having so many services in one place to talk to".

"Bringing everyone together under one roof, with a range top presentations to consider and the option to attend those that are most relevant."

"The speakers were very informative. The presenters did not read their presentations word for word but gave an overview which made it easier to take in the information. People were cheerful and very friendly."

"A huge amount of useful information, dedication, that every presenter provided, lots of brochures to take away from the fair and possibility to speak and to ask questions, friendliness of everybody, and it was so nice of you to offer tea and a lunch! Amazing event. It is my fourth time I think and I am ever so grateful!"

"Everyone was friendly, lots of useful information and people listened and gave you ideas/ help."

"Choice of workshops, great talks and good to see resources and chat to others"

"Being able to talk to professionals, and having a range of services in one room."

OUR FIGURES

INCOME

Donations and Legacies

Government Grant Income

Department for Education Grant	£23,968
Cambridgeshire County Council	£80,144

Other Grants

Huntingdon Freeman and Tesco	£5,560
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Charitable activities

Integrated Care ICS	£16,000
ADHD / ASD Support Sessions	£20,000

General Donations and Other Charitable Activities	£4,889
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TOTAL MONEY IN:	£150,561
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EXPENDITURE

Activity Costs	£12,434
Staff and associated costs	£122,269
IT and Communications	£6,960
Property and office costs	£10,919
Governance	£4,793
TOTAL MONEY OUT:	£157,375

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 parent carers 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 Statutory Assessment Team reorganisation on the back of feedback and a review of how to improve the service.*
- *welcomed the Statutory Assessment 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 Statutory Assessment 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 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 Neurodiversity booklet for parent carers to help them find services and support if they think their child may be neurodiverse.*
- *introduced more health information sessions, with topics selected from frequent feedback from parent carers.*
- *worked with the County' Council'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 direct to those who commission or work in the services they use.*
- *raised parent carer voices at the boards we attend and followed up with individuals as and when needed.*

- *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 Neurodiversity 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 Neurodiversity pathway work.*
- *have used some of our resources to enhance the information offered for parent carers through our free online sessions.*
- *invited a 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 children and 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 for Cambridgeshire.*
- *worked with the Integrated Care Board to provide parent carer voice to the Mental Health Key Worker programme.*
- *enabled co-production 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 YOUUnited 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 County Council on the back of us raising that there is a need for mental health support for children and young people with SEND needs .
- continued to focus a significant number of our sessions on the needs of SEND children with poor mental health and ways to help them. For example, session on ADHD and mental health, situational mutism, autism and mental health.

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, parent carers 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 the CCC website.*
- *have invited the PfA lead for CCC to attend every participation session with us to hear from parent carers 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 Neurodiversity booklet that is available to download freely providing Cambridgeshire specific information about support and services for children and young people with any Neurodivergent need.*
- *are working on developing a Cambridgeshire pathway for Neurodiversity assessments for children and young people.*
- *are co-producing with the LA on their SEND transformation programme to provide more, earlier, better intervention for children and young people with SEND in Cambridgeshire, 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.*

- *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 to regularly to our Mental Health and Education participation sessions to hear directly from parents and carers. This enables partners to feed 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.*
- *facilitated the Head of School Readiness and Early Years' Service to join Pinpoint at 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 Neurodiversity booklet with their staff and the families they support.*
- *have produced a Cambridgeshire specific Neurodiversity booklet that is available to download for free.*
- *are working closely with the Local Authority to embed parent carer voices into the All Age Carers strategy.*
- *continue to provide a non-judgmental safe space for parent carers to get support and information.*
- *provide regular parent carer sessions to increase the confidence of parent carers – parent carers are the experts.*

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 voices 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 after we stressed the 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, non-judgmental 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 Neurodiversity-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 Neurotypical.*
- *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. We 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.*

- 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.

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

- insisted that this must remain 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 that 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 parent carer's concerns with the LA regarding school attendance and exclusions.
- offered parent carers a session with LA officers to directly raise parent carer 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 parent carers needed.
- continue to provide weekly information sessions 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 parent carer 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 perspective.

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 Your wOn Health .
- are working with the LA to ensure the Local Offer SEND Hub incorporates video clips to explain the things you need know about.

You Said... it's 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 (ensuring a clear distinction from 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 Carer 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 carer assessments.*

You Said... it's hard to find what you need and the waiting times feel like forever. We...

- *develop our information sessions based on parent carer 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 parent carers.*
- *ask at each Pinpoint session what topics you would like to know more about and plan our timetable to this.*
- *know how complicated and difficult to navigate the system can be, so we delivered a session on Communicating Your Child's Needs to Professionals last month. Parent carers also wanted more around ADHD in school so it is 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.*

We will do our very best to continue to design our programme around what parent carers ask for -by parents for parents!



PINPOINT'S 2024 CONFERENCE



pinpoint

for parents by parents

