



2024

BETTER TOGETHER EVENT REPORT

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Introduction

The fourth Better Together event, held on March 28, 2024 at Kassam Stadium, witnessed its largest turnout yet, with over 130 families and professionals in attendance. This event is dedicated to fostering a collaborative approach between parent carers and service providers to improve support for children and young people with special educational needs and disabilities (SEND). It serves as a unique platform for parent carers to engage with professionals in meaningful discussions aimed at enhancing these vital services.

The event was funded and attended by the Local Area Partnership which includes:

- Oxfordshire County Council
- NHS Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB)
- Oxford Health NHS Foundation Trust
- Oxford University Hospitals NHS Foundation Trust (OUH)
- Oxfordshire Parent Carer Forum (OxPCF), the official body for the voice of parent carers.

By bringing together parent carers and service providers, the event encouraged a productive dialogue on current successes and potential areas for improvement. Attendees participated in three sessions covering key topics in Health, Education, and Social Care, reflecting issues identified as priorities by both families and professionals. This structured focus ensured that discussions were relevant and impactful.

Each table had a facilitator to guide the discussions, ensuring all feedback was accurately recorded. The Oxfordshire Parent Carers Forum (OxPCF) analysed and summarised this feedback, which is included in this report. The information was then shared with the Local Area Partnership (LAP) and in return they have shared their summaries and commitments which are detailed in this report.

The goal of Better Together is to create an environment where parent carers and service providers can work together constructively, driving meaningful changes to achieve better outcomes for children and young people with SEND. This report aims to capture the insights, discussions, and commitments from the event.

// JULES FRANCIS-SINCLAIR
OXPCF CHAIR

Introduction from the Local Area Partnership

Dan Leveson



Place Director for
Oxfordshire |
Buckinghamshire,
Oxfordshire, Berkshire
West ICB

Lisa Lyons



Director of Children,
Education & Families,
Oxfordshire County
Council

It was a pleasure to contribute to the Better Together event and receive this report. Our thanks and appreciation go out to OxPCF and all the parents and carers who organised the event and produced this report. Our thanks also go to all the parents, carers, professionals, and organisations who attended.

As members of the Local Area Partnership, we value the opportunity to listen to, discuss, and absorb the experiences and suggestions provided by parents, carers, and organisations who support our children with SEND.

Involvement and coproduction are central to SEND improvement and provide the chance to think about innovation and doing things differently. The contributions we heard on the day and the insights provided by the Better Together event are valuable and have already shaped our plans.

As we continue this journey, the contributions, inputs, and insights from parents, carers, and children and young people are like gold dust, and we look forward to ongoing collaboration.

The insights provided by the Better Together event are valuable and have already shaped our plans.

OxPCF's Summary of Feedback

Navigating the complex landscape of support services for children and young people with special educational needs and disabilities (SEND) in Oxfordshire can often be daunting for parent carers. Throughout the sessions, several recurring themes emerged, encompassing issues related to:



01. Communication and Information Provision



02. Continuity and Consistency of Support



03. Access to Services and Support



04. Transition Planning and Pathways



05. Early Intervention and Prevention



06. Collaboration between Services

Each theme reflects the multifaceted nature of the challenges encountered by parent carers as they strive to access appropriate support for their children. They also shed light on the challenges continually faced by families seeking support and highlight areas for improvement in the provision of services.

In the following sections, we delve into each theme discussed at the Better Together event in more detail for each service, exploring the concerns and insights provided by parent carers, as well as the implications for service provision and policy development.

Through a deeper understanding of these themes, we hope that the Local Area Partnership will ensure work towards implementing strategies through the SEND Transformation programme addresses the identified challenges and enhances the overall support system for children and young people with SEND and their families in Oxfordshire.

Services Represented

We had an amazing turnout at the event, with a large variety of services and organisations represented. Here's a look at who joined us alongside parent carers

Services:

- ✓ Oxfordshire County Council, Education
- ✓ Oxfordshire County Council, Social Care
- ✓ Start Well, Oxfordshire Health, Education and Social Care (HESC)
- ✓ BOB ICB (Buckinghamshire, Oxfordshire & Berkshire West ICB)
- ✓ Oxford University Hospitals NHS Foundation Trust
- ✓ Oxford Health NHS Foundation Trust
- ✓ Oxfordshire CAMHS (Child and Adolescent Mental Health Service)
- ✓ Oxfordshire SENDIASS
- ✓ Oxfordshire County Council Councillors
- ✓ Oxford Hospital School
- ✓ SENDIASS Oxfordshire (Special Educational Needs and Disabilities Information Advice and Support Service)

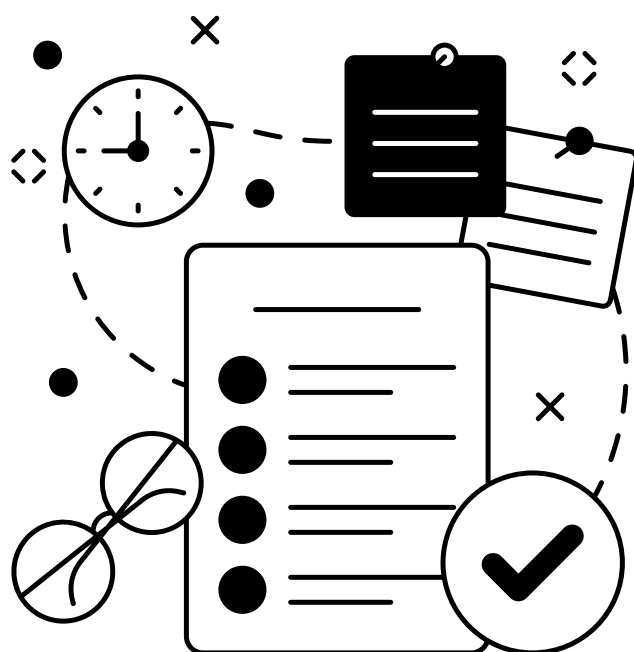
Organisations Represented

Organisations/Provisions and SEND Associated Businesses represented

- ✓ A New Way of Being
- ✓ Abingdon and Witney College
- ✓ Abingdon Carousel Family Centre
- ✓ AFiUK (African Families in the UK)
- ✓ Autism Champions
- ✓ Autism Family Support Oxfordshire (AFSO)
- ✓ Autism Oxford
- ✓ Bicester Autism
- ✓ Carers Oxfordshire
- ✓ Down's Syndrome Oxford
- ✓ Healthwatch Oxfordshire
- ✓ Helen and Douglas House
- ✓ Jaskulla Mentoring
- ✓ Laila Tyrrell Speech and Language Therapy
- ✓ Mental Health Natters
- ✓ Oasis Autism
- ✓ Oxford Creators
- ✓ Oxford Hub
- ✓ Oxfordshire Family Support Network (OxFSN)
- ✓ Oxfordshire Parent Carers Forum (OxPCF)
- ✓ Oxfordshire Youth
- ✓ The Harbour
- ✓ The Peeples Centre
- ✓ The Story Museum
- ✓ Tutor Doctor
- ✓ UTC (University Technical College, Oxfordshire)
- ✓ Yellow Submarine

Summaries

The feedback from each table during each session was collated and documented. All of this information can be found in the appendices. OxPCF has provided a summary for each table, which is available below for the service areas of Education, Social Care, and Health. Each service has then responded to the summary and the collected feedback.



OxPCF Education Feedback Summary

The discussions surrounding education particularly focused on communication, support, transitions, and the quality of services, highlighting both successes and challenges within the system.

Positive experiences were noted, especially when there is clear communication, transparency, and collaboration between parents, educational institutions, and support services. Early identification of needs, along with access to appropriate resources and interventions, is crucial for ensuring positive outcomes for children with special educational needs and disabilities (SEND).

However, several areas of concern were identified. These include inconsistencies in communication, delays in responses from SEN officers, and a lack of transparency in decision-making processes. Parents often find themselves advocating for their children, navigating complex systems, and feeling overwhelmed by the responsibility of ensuring their child's needs are met.

There are widespread calls for improved training for school staff, including SENCOs, and better access to support services for both parents and children. Additionally, the education system needs greater flexibility and adaptability to accommodate the diverse needs of children with SEND.

Overall, the discussions emphasised the importance of the following to ensure that children with SEND receive the quality education and transition support they deserve:

- 1. Unified efforts between services**
- 2. Clear communication**
- 3. Proactive support**

Addressing these key areas will help create a more effective and supportive educational environment for children with SEND.

Summary response from the Education Service, Oxfordshire County Council

We acknowledge and welcome the feedback provided through the table discussions as an opportunity to further enhance the efficiency and effectiveness of the services we provide.

We have considered and broadly agree with OxPCF's summary of the feedback but would also like to add that in the past six months, we have undertaken a lot of work to improve communications with parent carers, with a greater focus on speaking directly with parent carers in a timely manner and responding promptly to emails.

This culture change work is on-going, and we expect the improvements to be reflected in the parent carer surveys undertaken in the future. Furthermore, under the broader remit of the transformation programme, there are a number of projects, the focus of which includes

- 1. Improve the capabilities of professionals in schools working with Children and Young people (CYP) with SEND**
- 2. Improve the quality and timeliness of EHCPs, including the panel decisions**
- 3. Building a digital interactive map of SEND pathways across all ages, stages, needs and provision.**
- 4. Working with the family of schools in Oxfordshire to include development of an education and inclusion strategy.**

We are confident that that the work planned and in progress will address all issues raised in the feedback from the event and as such do not propose any additional commitments.

OxPCF Social Care Feedback Summary

In examining the discussions surrounding social care, several critical themes emerged, emphasising the need for improved accessibility, communication, collaboration, and long-term strategic planning to effectively support children and young people with special educational needs and disabilities (SEND).

- 1. Improving access to information and resources:** Parent carers expressed a need for clearer, more accessible information about available support services and resources, including easy-to-understand materials, decision trees, and flow charts. Lack of knowledge about support options and roles of professionals remains a significant challenge.
- 2. Enhancing communication and engagement:** Parent carers highlighted the importance of regular updates, proactive communication, and personalised responses from services. Expected response times to inquiries, adaptation of out-of-office replies, and more proactive check-ins with professionals were emphasised.
- 3. Fostering greater collaboration and support:** There is a call for services to reach out to families more proactively, provide regular check-ins with professionals, and involve key workers or experts by experience. Collaborative efforts between services and parent-led groups were seen as essential for effective support.
- 4. Prioritising early intervention and accessibility:** Parent carers noted a lack of early intervention and identification of needs, highlighting the importance of warm handovers and better access to social care disability services.
- 5. Long-term strategy and improvement:** Discussions centered around the need for implementation of longer-term strategies, including more regular events, better integration of living well with neurodivergent initiatives, and improved transparency in data management and resource allocation.

In examining access to services, communication, quality of services, and transitions within social care, it is evident that a holistic, collaborative approach is necessary to address the diverse needs of children and young people with SEND effectively. Enhancing accessibility, communication, and collaboration while prioritising early intervention and long-term planning are crucial steps towards improving outcomes and support for this vulnerable population.

Summary response from the Children's Social Care, Oxfordshire County Council

We acknowledge and welcome the feedback provided through the table discussions as an opportunity to further enhance the efficiency and effectiveness of the services we provide.

We have considered OxPCF's summary of the feedback above and respond as follows:

1. The transformation programme has initiated a cross-cutting workstream to develop a digital interactive map of SEND pathways across all ages, stages, needs and provision. It will be published to the website as an interactive tool, which will provide parent carers with the ability to intuitively access essential information and their support decision-making
2. As part of a wide ranging programme across the whole Council, we are improving customer contact, customer experience and associated contact channels, including use of web self-serve, phone, email and face to face.
3. Children's Social Care is about to undergo a transformation of its operating model, partly in response to the 'Stable Homes, Built on Love' agenda, but also in response to the recent OFSTED ILACS inspection (judged Good). A key element of this work is further development of the Family Help service, which is predicated on the provision of earlier help and support to families, including CYP with living with disability.
4. The directorate has established an Early Help & Prevention Strategy and Board, including early years. This important change will ensure that CYP needs are identified and supported earlier.
5. The directorate has recently developed a strategy and improvement plan 2024-27, which brings together in one place a focused set of objectives and outcomes and the various programmes and initiatives that we will undertake to achieve them. These include the SEND Transformation, Stable Homes transformation, as well as a number of enabling strategies such as early help and prevention, transitions, commissioning, data strategy and reporting.

We are confident that that the work planned and in progress will address all issues raised in the feedback from the event and as such do not propose any additional commitments.

OxPCF Health Services Feedback Summary

The discussions around health services, communication, access, transitions, and support underscore the critical need for clarity, collaboration, accessibility, and consistency within the healthcare system.

- 1. Communication clarity and accessibility:** Parent carers emphasise the necessity of clear communication regarding available services, waiting times, diagnoses, and transitions, particularly in mental health services. There is a call for a single point of contact for parents and improved communication about support options.
- 2. Collaboration and coordination:** Parent carers highlight the importance of collaboration among health, social care, and education services for better signposting and coordination. Issues with communication between different services, such as CAMHS and SEND teams, are identified, emphasising the need for child and young person-centered decisions.
- 3. Technological solutions:** There is a suggestion for technological solutions, such as centralised apps or websites for child records, to improve accessibility and information sharing across services. Challenges with existing systems and the effectiveness of text reminders are also noted.
- 4. Professional awareness and sensitivity:** Parent carers emphasise the importance of professional awareness and sensitivity, particularly regarding appropriate communication methods, advocacy barriers for parents, equity in services, and support post-diagnosis.
- 5. Support post-diagnosis:** Discussions highlight the availability of support options post-diagnosis, including community support programs and educational sessions for parents.
- 6. Transparency and accessibility:** Challenges in healthcare access, communication, educational support, and professional training are identified. Parent carers call for greater transparency of processes, clearer pathways, and improved accessibility to specialised services and support.
- 7. Integrated approach to transition and support:** There is a consensus on the need for an integrated approach to transition and support, involving multiple agencies such as health, education, and social care. Key improvements include clearer discharge plans, support for carers, enhanced professional training, and improved communication between services.

In conclusion, addressing the identified challenges and improvement opportunities requires concerted efforts to enhance communication, collaboration, transparency, and support within the healthcare system. A person-centered approach, coupled with technological advancements and improved professional awareness, can contribute to better outcomes and experiences for children, young people, and their families navigating the complexities of healthcare transitions and access to services.

Summary response from the Health Services (Oxford Health NHS Foundation Trust, Oxford University Hospitals NHS Foundation Trust and Buckinghamshire, Oxfordshire and Berkshire West ICB)

We heard and value the many 'stories' and experiences shared through the Better Together event and we acknowledge how varied these can be for different CYP, families and carers. Health partners are committed to continue improving the effectiveness and accessibility of the services we commission and provide collaboratively across the Local Area Partnership.

During the past six months, we have taken several steps on the transformation journey as a local area partnership. There are a number of work streams within the Transformation programme and specifically within Right Provision, Right Time, Looking to Independence Theme Group that have been designed to address many of the issues raised, including transitions. We have acknowledged that health care 'transitions', particularly for those moving from CYP to adult services can be difficult. We will ensure that transitions are person centered and needs based to enable individuals to receive the most appropriate and beneficial interventions for them.

In addition, we have identified the following Health goals to address a number of key themes:

Improving 'communication' and increasing understanding of what services offer:

1. We heard that young people and families find it difficult to navigate around Services and they don't know what is available and how to access it whilst they wait. We are specifically looking at how we share 'what' is available for 'whom' and 'how' it can be accessed and recognise the need to work together to ensure there are effective information sharing processes across Health services and the Local Area Partnership.
2. Across Health Teams, we are working hard to better listen and understand what information families and carers need whilst 'waiting', focusing on accessible content (digital, written & pictorial forms), when we communicate, and how to do this effectively.
3. There are misconceptions about what services offer and we need to further promote what services do and don't do including at points of transition for children to adult services. We are working in partnership to explore how to 'myth bust', how to advertise, to update the Local offer, and to produce accessible materials that are available throughout our communities.

Ensuring Health professionals have the skills and capabilities to support children and young people with SEND. We are working with teams that span children and adult services to embed SEND training. The programme will encompass a mix of the Oliver McGowan Training, Council for Disabled Children (CDC) SEND programme, and National Health Service England (NHSE) SEND modules.

Establish a greater understanding of capacity and demand in services that CYP with SEND commonly access. Through doing this we will then be able to optimise what capacity we do have, and ensure we maximise opportunities to increase resources as they arise.

OxPCF is well represented within the Right Provision, Right Time project Theme Group and various projects within it. We look forward to better understanding the issues raised and considering how we can make further improvements going forward.

Panel Members



At the conclusion of the event, we facilitated a panel discussion featuring key service leaders. The panel members included:

Name	Service	Role
Lisa Lyons	Oxfordshire County Council	Director of Children's Services
Kate Reynolds	Oxfordshire County Council	Interim Deputy Director of Education
Deb Smit	Oxfordshire County Council	Head of SEND
Cllr Kate Gregory	Oxfordshire County Council	Cabinet member for SEND Improvement
Karen Fuller	Oxfordshire County Council	Director of Adult Social Care
Victoria Baran	Oxfordshire County Council	Deputy Director of Adult Social Care
Ian Smart	Oxfordshire County Council	Transformation Programme Director
Rachel Corser	Buckinghamshire, Oxfordshire and Berkshire West ICB	Chief Nursing Officer:
Chris Wright	Buckinghamshire, Oxfordshire and Berkshire West ICB	Ass. Director Partnership Development Oxfordshire
Grant Macdonald	Oxford Health	Chief Executive
Vicky Norman	Oxford Health	Head of Service Oxfordshire CAMHS and Eating Disorders
Mark Chambers	Oxford Health	Head of Children's Community Services
Sarah Haden	Oxford University Hospitals Trust	Consultant Community Paediatrician
Steve Crocker		Independent Chair of SEND Strategic Improvement and Assurance Board

Panel Reflections and Next Steps/Actions

Pledge from Martin Reeves, Chief Executive of Oxfordshire County Council

Martin pledges to use his influence and position to bring into the mainstream the work and voices of OxPCF and feed this into Oxfordshire County Councils' commitment to championing future generations in all we deliver in the county.

The Future Generations Commissioner for Wales – Acting today for a better tomorrow - more on future generations can be found [here](#). We are the only local authority in the country to have future generations as a cabinet member responsibility.

Kate Reynolds

Reflection: The importance of clear and open communication for effective collaboration and support.

Next Steps/Actions: Prioritise improving communication and fostering a respectful and caring culture within the SENO casework team, shifting the team culture towards one that values respect and empathy.

Deb Smit

Reflection: The critical need to empathise with parents and acknowledge their emotions during interactions.

Next Steps/Actions: Pledge to prioritise improving team practices to ensure better support and communicate with parents, recognising the importance of basic communication and courtesy.

Kate Gregory

Reflection: The significance of communication and transparency, especially through interactions with parents.

Next Steps/Actions: Support the team in enhancing communication and advocacy for parents and carers of children with special educational needs, despite not being in an operational role.

Ian Smart

Reflection:

- Acknowledgement of the responsibility and privilege of facilitating necessary changes and the importance of colleagues in implementing these changes and the importance of the leadership role ensuring that the system functions effectively.
- Understanding that no single person comprehensively understands the system, emphasising the need for collective effort in creating a clear picture for all.

Next Steps/Actions: Lead efforts to create a comprehensive understanding of the system through co-production, emphasising the collective effort needed for effective change.

Lisa Lyons

Reflection: Emphasises on the early stages of the partnership and the dedication shown by all. The commitment from school leaders to drive improvements in the school system, even during breaks.

Next Steps/Actions: Use the inclusion and educational strategy as a framework to enhance the school system in Oxfordshire. A commitment to parent carers to publish the plan on the page and milestones in May. (This can be found [here](#))

Panel Reflections and Next Steps/Actions continued

Chris Wright

Reflection: The importance of personalised care and support, and the challenges of providing this within the current regulatory framework.

Next Steps/Actions: Foster relationships that prioritise the best interests of parents, children, and families, aiming for a more personalised approach to care and support.

Grant Macdonald

Reflection: The complexity and difficulty in navigating CAMHS services, and the need for simplifying internal processes.

Next Steps/Actions: Simplify services to make them easier to navigate, validate the experiences of users, and balance the importance of diagnosis with prompt support and treatment. Open and honest discussions will be prioritised to address challenges and improve services.

Karen Fuller

Reflection:

- The impact of effective communication and the gap in understanding among parent carers about available resources.
- The need for improved coordination and communication within the system to ensure that information reaches to those who need it.
- Highlighting the transition handbook, Moving into Adulthood, developed in collaboration with OxFSN which can be found [here](#)

Next Steps/Actions: Commitment to collaborate with OxFSN to improve communication strategies, provide refresher training of consistent and effective communication

Victoria Baran

Reflection: The impact of everyday tasks on the lives of service users and the consequences when these tasks are left undone.

Next Steps/Actions: Simplify systems and processes to empower staff, ensuring they can focus on essential tasks without feeling overwhelmed. Commit to supporting staff effectively so they can fulfil their roles without experiencing feelings of failure.

Steve Crocker

Reflection:

- Acknowledges that progress is still in the early stages likening the current stage being in the 'foothills' of the journey towards improvement. Recent developments include the appointment of senior roles and the establishment of structures and governance to guide the improvement efforts of the Local Area Partnership.
- Emphasises the important of sustained effort in implementing changes and acknowledges that significant progress will take time

Addressing Key Questions

The panel received the following questions from parent carers and professionals in attendance:

When will parents start to feel an improvement in SEND Support and how will you know what you're doing to improve things, has made a difference?

Kate Reynolds

- Progress in SEND Support: Implementation of major programmes aims at shifting school cultures through relational work, facilitating the sharing of good practices, and collaborating with chief executives of multi-academy trusts to ensure systemic culture changes. Acknowledgement that culture change takes time but steps including the enhanced pathways, relational schools and SENCO training to provide educators with more information and support are making an impact.

Deb Smit

- Framework for Support: A central framework will be launched in September, providing professionals with comprehensive advice and support across four broad areas of needs: Communication and interaction, Cognition and learning, Social, emotional and mental health (SEMH), and sensory and/or physical.
- A SENCO help desk and distribution of a fortnightly SENCO newsletter.
- Implementation of enhanced pathways to support children in mainstream schools and initiate a special school outreach programme to aid mainstream schools and improve communication with parents and carers.
- Launch of a special school outreach program where special school staff support mainstream schools

Are any of these provisions being made available accessible for early years?

Deb Smit

- Approximately half of the current enhanced pathways are designated for Key Stage One. While they do not extend to nursery settings, pilot programmes in Banbury and Didcot focus on early years SEND support, auditing practices, and providing guidance and training based on identified areas for improvement.

Addressing Key Questions

Who is responsible for putting alternative provision in place and how do parents actually access that for their children, how do they make sure that the issue is just not ignored and passed on between the school and the council in a never-ending process?

Lisa Lyons

- Organising alternative provision is typically the school's responsibility for short-term interventions or additional support. For permanently excluded children, it falls to the local authority, usually through pupil referral units.
- Efforts are ongoing to improve communication and ensure appropriate support for students needing alternative provision and guidance is being created by SENDIASS and OxPCF for parents to understand and navigate the process.

When are Ofsted expected back in for the monitoring visit and what will you tell them?

Lisa Lyons: The visit date is unannounced, but expected in about 18 months. Progress will be evident through a clearer picture shaped by parental feedback and incremental improvements. Dialogue with Ofsted and CQC will highlight ongoing enhancements since the last assessment.

Rachel Corser: There is regular engagement with Ofsted and CQC (Care Quality Commission) and the Local Area Partnership ensuring continuous interaction and accountability

Do CAMHS have an active objective, along with a realistic target as to how you're going to reduce those waiting times and if you do, what is your realistic target?

Grant Macdonald: Targets are set, but significant changes to processes are needed to reduce waiting times. Currently, 2,477 individuals are on the waiting list, with an average wait of two years and even longer for most people. Efforts are focusing on providing immediate support without needing a diagnosis and prioritising cases based on need.

Vicky Norman: Neurodevelopmental assessment pathways are robust, with 97% of children receiving a diagnosis. Efforts include holistic approaches, prioritisation of medication for ADHD, and a Living Well with Neurodivergence offer to support families during waiting periods - info on this can be found [here](#). Urgent cases are treated within national guidelines to minimise risks.

Event Feedback

How did you find the sessions and the event in general?

Well run, participants felt comfortable to speak openly

Everything was amazing, such consideration was given to who was attending

insightful
collaborative

emotive
exhausting
useful
interesting
frustrating
productive
interested
sad
powerful
interactive
discussion
good
helpful
communicative
positive
amazing
safe
respect
traumatic
difficult
thought
thinking
enlightening
broadened
understanding
facilitated
constructive
provoking
thoughtful

Provided the opportunity for productive, honest conversations.

So very well organised and so much thought had clearly gone into the event to ensure that it was accessible.

Acknowledgements

We want to take this opportunity to thank the following for their invaluable support and contribution:

- First, our heartfelt thanks to the committed and passionate parent carers who shared their experiences and enriched the conversations in the room. Your voice and your child's voice are crucial in driving the important discussions about necessary improvements.
- Secondly, we extend our gratitude to all the professionals who attended the event, listened respectfully to the parent carers, and demonstrated their passion and commitment to placing the child at the centre of their decision-making.
- Special thanks to Gail Hanrahan from OxFSN for facilitating the event with expertise and dedication.
- We are incredibly grateful to our AMAZING facilitators and scribes who worked tirelessly to ensure that all voices were heard and that the important conversations were productive and inclusive.
- A big thank you to Marshlings Sensory World for supplying the wonderful goodie bags. The thought and care put into them were greatly appreciated by everyone.
- We also want to express our sincere appreciation to the Local Area Partnership for funding this event and for their commitment to attend the event and produce summaries.
- Lastly, our sincere appreciation goes to all the volunteers from the Oxfordshire Parent Carers Forum who dedicated countless hours to preparing and running the event. Your hard work and commitment made the event a success.



THANK
YOU

Event Attendees: Organisation and Business Contacts

- Oxfordshire Parent Carers Forum: www.oxpcf.org.uk
- Oxfordshire Family Support Network: www.oxfsn.org.uk
- Oxfordshire SENDIASS: <http://sendiass-oxfordshire.org.uk>
- AFIUK: <https://afiuk.org>
- Autism Champions: <https://www.autismchampions.co.uk>
- Autism Family Support Oxfordshire (AFSO): www.afso.org.uk
- Autism Oxford: <https://autismoxford.com/>
- Bicester Autism: <https://www.bicesterautismadhd.co.uk>
- Carers Oxfordshire: <https://www.carersoxfordshire.org.uk>
- Down's Syndrome Oxford: <http://www.dsoxford.org.uk>
- Healthwatch Oxfordshire: <https://healthwatchoxfordshire.co.uk/news>
- Jaskulla Mentoring: <https://www.jaskullamentoring.co.uk>
- Laila Tyrrell Speech and Language Therapy: <https://lailatyrrellslt.co.uk>
- Mental Health Natters: <https://www.mentalhealthnatters.org>
- Oasis Autism: <http://oasionline.org.uk>
- Oxfordshire CAMHS Service: www.oxfordhealth.nhs.uk/camhs/oxon/
- Oxfordshire County Council SEND Improvement Updates:
<https://www.oxfordshire.gov.uk/residents/children-education-and-families/oxfordshire-send-local-offer/send-strategy/send-improvement>
- Oxford Creators: <https://oxfordcreators.co.uk>
- Oxford Hub: <https://www.oxfordhub.org>
- Oxfordshire Youth: <https://oxfordshireyouth.org>
- The Harbour: <https://www.oxford-harbour.org>
- The Peep Centre: <https://www.peep.org.uk/peep-groups-oxfordshire>
- Tutor Doctor: <https://www.tutordoctor.com>
- Yellow Submarine: <https://www.yellowsubmarine.org.uk>

Appendices

The following appendices present the collated feedback from the table discussions during the Better Together event. This input provides valuable insights and perspectives from parent carers, highlighting key areas for improvement and future focus. All feedback was shared with the Local Area Partnership, contributing to their summaries and commitments. OxPCF has summarised this feedback for inclusion in this report.

Appendix 1: Education Table Feedback

Education: Communication

Communication and Transparency

1. Acknowledgement of emails received
2. Clarity on how the system works for parents and children/young people + transparency on the processes involved (pathway mapping workstream)
3. Transparency on how the Local Area Partnership is reviewed and how services are being delivered (programme governance)
4. Emails consistently being ignored
5. Opportunities to meet SEN officers face to face/online for Q&A sessions
6. Schools need to listen to parents. Even after diagnosis, children's needs are being ignored because they mask at school
7. Share key performance indicators so parents know what to expect
8. Transparency on the panels process to prevent frustration from families
9. Courtesy emails to be sent to advise that they are dealing with the case
10. Full info to be given to explain why things are happening in the school setting
11. Factual signposting
12. Consistently respond to all questions asked with a named person
13. An EHCP type document for those under SEN review at school to agree child's needs and what is currently being provided
14. OCC portal to be up to date, functional, regularly maintained with good turnaround for responses
15. Basic business practice from SEN officers in terms of auto replies on all emails, when there are staff changes, email inboxes to be monitored by admin staff when out of office to remove uncertainty and frustration
16. Communication via email or portal - NOT EGRESS which is not accessible

Professional Development and Support

1. Feedback sessions with parents - how do we achieve these conversations?
2. Action plan of annual reviews to include training schools in the annual review process
3. Increase the use of the portal to include communications rather than using EGRESS
4. Consistent support not just "ticking boxes once a term" to remove the ongoing stress from parents
5. Proactive not reactive
6. Restorative practice is needed and acknowledgment of the impact on the family
7. Constructive rebuilding of trust with SEN officers after issues to maintain young person's and parent carers trust in adults
8. Comms need to be factual and punctual so timeframes can be met and not to give false hope to families
9. SENCO training on applying for EHCP, annual review process, accessing alternative provision
10. SENCO training on listening to parents, signposting families and communicating with SEN officers
11. SEN Training hub co-produced by parents for parents, SENCOs/SEN officers coordinated by parents who understand and can explain things in the right way.

Appendix 1: Education Table Feedback

Education: Communication continued

Process Improvement and Guidance

1. An open dialogue to manage expectations (on both sides)
2. Confirm process of consultations and what are the Next Steps/Actions
3. When change of placement is raised at AR (Annual Review) - involve EHCP officer
4. Improved process for transitions from early years onwards
5. Mediation service offered by OCC to help communicate/mediate between family/schools to prevent frustration/stress
6. Outreach training
7. Webinar/information booklet around the process, who are the SEN Officers, what is their role, the processes, more transparency, plain language and clarity
8. More awareness of EOTAS and options when school placement fails - having to self-navigate is exhausting and signposting is poor
9. Consistent understanding of SEND Law and the Code of Practice
10. Understanding that if a parent is in an appeal situation, they would already be at crisis point
11. A way to track and know who is involved in the process so you can kept up to date and ensure the correct people are involved/consulted in the care and educational help your child needs

Collaboration and Involvement

1. Team around the child/young person/family - needs to include an EHCP officer
2. Professional code of conduct should be co-produced and signed off - service level agreements to include turnaround times, consistency etc.
3. Series of videos/resources for mainstream academy schools
4. Schools to explain if professionals are seeing the child, what they are doing/the process etc.
5. Clarity on where the child/young person sits re getting provision
6. Signposting for private options/guidance around what options are available/accepted re Educational Psychologists, CAMHS, Diagnosis etc.

Appendix 1: Education Table Feedback

Education: Access to Services

Holistic Approach and Individual Needs

1. Consider children's needs holistically
2. Some children/young people who have diagnosis need an EHCNA to get an EHCP irrespective of mainstream or not
3. Consider knock-on effects of a child being out of education or in part-time education on the child but also the family (loss of earnings etc.)

Resources and Funding

1. Schools need more resources/funding to put appropriate support in place
2. More alternative provision available for those that cannot access education with appropriate APs (Alternative Provisions) that suit a child-by-child basis

Parental Expectations and Support

1. Expectation of parent is that professionals know the information and support families properly
2. LA needs to change attitude to "How can we help?" instead of parent carers feeling of them not helping at all
3. Better support when going through tribunal - feels like children are left on their own and no longer supported. SEN officers support needs to continue

Legal Compliance and Procedures

1. LA needs to accept they need to review their approach to the EHCNA process/criteria
2. Follow the law, in particular, section 19
3. Phased transfer - meeting deadline for this and better communication to parents
4. LA needs to plan the provision based on the current demand

Training and Education

1. LA to facilitate teacher training sessions on SEND
2. Training on masking by CAMHS to schools/other educational provisions
3. SEND training at all levels - from headteachers, teachers, teaching assistants and school staff such as dinner ladies and receptionists
4. Schools need training on how to access services
5. Training for schools to deliver sensory interventions
6. Schools need the same training in things that can be implemented into schools day to day like OT support
7. More proactive steps to be taken from early years
8. Better SEND training in early years - settings need to stop telling parents they can't get an EHCP before they are in school
9. Education with school staff on ASD, in particular around masking and the PDA (Pathological demand avoidance) profile of autism

Appendix 1: Education Table Feedback

Education: Access to Services continued

Transition and Post-16 Options

1. More post-16 options, better access to services/transition to next stages: college and adulthood

Collaboration and Communication

1. Schools need a clear line to work too - they all do things differently
2. LA to work with schools and settings to better understand EBSA needs and barriers
3. Look at doing some workshops with parents regarding alternative provision
4. Schools to provide better education options on their roll list - this is a requirement and school should have more resource
5. Schools to buy in independent services to meet the child's/young person's needs
6. Communication within SEND teams needs to improve
7. Offer a form of mediation for schools to communicate with parents when things are not going to plan
8. One point of contact for each child, a care and education coordinator

Financial Management and Accountability

1. Map of where funding is going
2. Transparency on how funding of EHCP is being spent and used

Resource Allocation and Support

1. SENDIASS need more resources
2. SENCOs need better training
3. More people who are able to assess children/young person
4. Schools need more than one SENCO per school - level of need is higher than in previous years
5. Better SEND training in early years - settings need to stop telling parents they can't have EHCP before they are in school!

Consistency and Prevention

1. Consistency
2. Intervention as prevention and not when something has gone terribly wrong
3. When it's clear that a specialist setting is needed - not to be rejected straightaway
4. Schools not avoiding/rejecting when a child has needs
5. Parent blaming

Information and Transparency

1. More information regarding Alternative Provision - who is responsible for this early on, who is responsible for putting a plan in place, who actions the start of the provision
2. Accountability

Appendix 1: Education Table Feedback

Education: Quality of Services/Support

Positive Support and Experiences

1. Feedback of a great SEN officer with excellent communication and transparency.
2. Positive experiences with OCC SEN Base meeting son's needs.
3. Early access to support for a daughter diagnosed with deafness, including a supportive teacher for the deaf.
4. Appreciation for the Early Years Support Team's frequent communication and assistance during COVID-19.
5. Success in mainstream school for a granddaughter with a rare syndrome, receiving 1:1 support.
6. Positive experiences with SENDIASS, highlighting accessibility and advocacy.
7. Importance of parent-carers knowing the law and being kept informed.

Early Identification and Intervention

1. Recognition of the need for earlier identification of needs and access to diagnostic services.
2. Advocacy for more resources and training for SENCOs, including access to Educational Psychologists.
3. Calls for integrated early intervention strategies and clearer guidance on assessment processes.

Collaboration and Accountability

1. Advocacy for greater collaboration between SEN officers, families, and support services.
2. Concerns about inconsistency in EHCP reviews, lack of accountability, and the need for SEN officers to attend meetings.
3. Emphasis on transparency in data management and resource allocation.
4. Team Around the Child to be functional

Transition Support and Equality

1. Recognition of challenges and inequalities in transition processes between schools.
2. Advocacy for standardised transition practices, better support for complex children, and early planning for transitions.
3. Concerns about the timing and quality of EHCP reviews, as well as reluctance to quantify needed provisions.

Information and Awareness

1. Importance of access to accurate information, knowledge of the law, and support services for parents.
2. Recognition of the role of voluntary sectors
3. Educational sessions on alternative provisions and mental health support available
4. Advocacy for better training for SENCOs, clearer guidance on policies, and improved communication between schools, SEN officers and parents.

Appendix 1: Education Table Feedback

Education: Transitions

Transparency and Communication

1. Transparency of actions
2. Online portal (part of meetings to support)
3. Accountability for meetings with clear timeframes
4. Conversations earlier and communicated with all Parent carers
5. SEN officers not coming to annual reviews at transition points
6. SEN officers out of county so have no local knowledge

Support and Resources

1. More SEN Officers/Transition specialists
2. Advocate (SENDIASS overwhelmed, needs more resource/funding) to help with parent relationships with educational provisions
3. Alternative provision is good but have to find for ourselves
4. No support for children who are NEET/School refusing
5. More education for teachers
6. Enhanced provisions - different environment to learn
7. Sensory needs: Understanding adaptations
8. Individual learning mentor
9. Summer holiday club for children with SEND to help with transitions in settings

Empowerment and Advocacy

1. Parents don't have any info given to them regarding transitions
2. Parents feel like they are fighting each transition
3. Other professionals listened to ahead of parents, parents voice needs to be valued/respected
4. Young person's voice needs to have equal value, not be singled out
5. Punitive punishments in terms of attendance such as missing out on prom needs to be stopped
6. Schools need to know what support is out there
7. Informal support needs to be formal and held accountable
8. Lobby government for more funding

Training and Awareness

1. More education for teachers
2. SEN officers not coming to annual reviews at transition points
3. SEN officers out of county so have no local knowledge
4. Ed Psych need to be more involved with transitions to improve consistency

Appendix 1: Education Table Feedback

Education: Transitions continued

Flexibility and Adaptability

1. More flexibility, more resources, transitions earlier and timeframes longer
2. Rules to be adaptable
3. Schools need to be supported to be more flexible

Specific Transition Needs

1. No post 16 option at Bishopswood
2. No options when on the border
3. Good: Parents listening and understanding. Child first relationship
4. Shuffle up days - good idea
5. Extending offer to all students but do schools know/take it up?
6. Central database needed for all info on SEND
7. School don't have a clue - parents have to tell them what is needs to be done
8. The big change between primary and secondary needs to be recognised
9. Young person needs emotional support
10. Smaller provisions needed for CYP who struggle with large numbers of peers
11. Schools need to be supported to be more flexible
12. Systematic response to change culture is desperately needed
13. Senior leadership - whole school approach
14. SEND Transitions periods - Year 5 into Secondary and then Year 10 to Post 16 provision
15. Schools to employ transitions key worker
16. 3 days offered for transitions
17. Pilot scheme/model for transitions

Appendix 2: Social Care Table Feedback

Social Care: Communication

Improving Access to Information and Resources

1. Easy read versions, decision trees, and flow charts of processes to enhance understanding.
2. Lack of knowledge about available support/resources and roles of different professionals.
3. Need for basic leaflets and non-digital options for parents/carers.
4. Info needed on how to access all teams involved with children/young people.
5. More pro-active check-ins with professionals.
6. Third sector organisations like Bicester Autism, Oasis, AFSO, and Mabel Pritchard Parent Carer group are valuable.
7. Pack for parent carers who have children with SEND.
8. We only know about things due to groups like Oxfordshire SEND Room

Enhancing Communication and Engagement

1. Regular updates and more proactive communication needed from services.
2. Multi-facilitated communications and personalised, pro-active responses desired.
3. Expected response times to emails and adaptation of out-of-office replies.
4. Lack of training in SENCO's responsibilities and improvement in experience of comms with social care.
5. Parent carer forums/support groups within schools.
6. Good experiences highlighted with the communication and support from Moving into Adulthood team
7. Timely response to emails and phone calls needed

Fostering Collaboration and Support

1. Services should reach out to families and provide more regular check-ins with professionals.
2. Importance of key worker/expert by experience voices and parent-led groups for support.

Prioritising Early Intervention and Accessibility

1. Lack of early intervention and identification of needs by social workers.
2. Need for warm handover and better access to social care disability services.

Long-term Strategy and Improvement

1. Implementation and actions needed for longer-term strategy and improvement.
2. More regular Better Together events and improvement in Living well with Neurodiversity/Neurodivergence offer.

Appendix 2: Social Care Table Feedback

Social Care: Access to Services

Accessing Support Services

1. Difficult to access children's social care.
2. Many children with SEND lack access to respite, holiday clubs, or activities.
3. Challenges in finding support or services and coordinating them as a parent.
4. Lack of awareness about available support/resources.
5. Need for a single "front door" for access to social care.
6. Transparency needed around criteria for support.
7. Disparity in support and need for consistency.
8. Need for more funding directed to social care.
9. Importance of voluntary sector organisations for support.
10. Utilising Sure Start children's centres.
11. Community hubs/centres needed to provide local support.
12. Clear signposting and single "front door" access to services.
13. Transparency in criteria for accessing support services.
14. Joining up processes of different budgets for better support.
15. Database of unmet need to highlight challenges in the system.

Timeliness and Transparency

1. Delays mean support is not timely.
2. Waiting lists can cause anxiety; need for honest updates.
3. Clarity, honesty, and transparency needed across all services.
4. Need for transparency in criteria for support.
5. Clarity around what is available and how it can be accessed.
6. Reviewing policies around personal budgets and direct payments.

Holistic Approach and Coordination

1. Importance of a holistic approach and "Think Family" perspective.
2. Parents need support coordinating various services.
3. Functional support like laundry assistance needed.
4. Incorporating early help workers' views into social care assessments.
5. Recognising and supporting familial neurodivergence.

Training and Education

1. Need for training professionals in autism-specific approaches, trauma-informed care, and sensitivity around language.
2. Education and training for teaching assistants (TAs) and school staff.
3. Training on available local support services for professionals.

Appendix 2: Social Care Table Feedback

Social Care: Quality of Services

Clarity and Transparency:

1. Clarity of information
2. Transparency
3. Clear pathway
4. Transparent criteria
5. Annual reviews – updating EHCPs
6. Explaining what a family can expect
7. Providing clear and accurate information
8. Consistency of quality within and across teams
9. Effective signposting
10. Realistic EHCPs that are delivered
11. Opportunities to provide feedback to OCC
12. Use contributions of people with lived experience
13. Reduce waiting lists
14. Explain what is available – easy, clear system

Holistic Approach and Collaboration

1. Looking at a child holistically
2. Services that talk to one another and work together
3. Joined up thinking and finances – health, education, social care
4. Use a trauma informed approach consistently
5. Have a holistic view
6. Multidisciplinary teams working together

Advocacy and Support

1. An advocate for all to walk alongside the young person
2. Plug gaps in services
3. Offer alternatives
4. Provide mentoring for young person – look at the child as individuals
5. Listen to parents
6. Be person centred, not just box ticking
7. Asking for parents thoughts, views etc and then ignoring them

Appendix 2: Social Care Table Feedback

Social Care: Quality of Services continued

Communication and Listening

1. Listening and understanding
2. Clarity
3. Simplicity of information
4. Good communication
5. Going over and above
6. Consistency of carer
7. Don't over promise
8. Ability to deliver a difficult message well
9. Honesty, even if it's a difficult message
10. To be listened to and valued
11. To be given a voice
12. Help! If you ask for help it should be given
13. Allowed to change your mind
14. Hear the frustration - don't say it's not our problem

Addressing Systemic Issues

1. Long term planning – improve the year 9 onwards process of planning for transition,
2. Improve post-18 options and support
3. Avoid delays to preventative work
4. Earlier referrals to complex needs
5. Reduce waiting lists
6. Addressing gaps in services
7. Challenging systemic issues such as racial profiling and binary categorisations

Appendix 2: Social Care Table Feedback

Social Care: Transitions

Communication and Information Provision

1. Better understanding of language and information to help parents
2. Parents don't know what will happen when their child turns 18
3. Parent don't know what the result of the referral will be
4. Need to have contact details so that parents can chase up if they have not heard back from social care
5. Schools not giving any information
6. Inconsistency of depth of knowledge regarding the young person in the EHCP process
7. Transition information not shared early enough
8. Data from children's services to adults needs to come through earlier
9. EHCP not being adhered to by schools
10. Communication very important
11. Across the board, information is not clear
12. Useful/helpful if the social worker could have more answers to questions

Continuity and Consistency of Support

1. Consistency of staff would help as there is fast turnover of SEN officers
2. EHCPs are not necessarily giving a good reflection of the person
3. Denied an assessment until child becomes dangerous - reactive system only
4. System only intervenes at crisis point and then leaves too quickly

Access to Services and Support

1. What happens if you get to get a referral form (continuing health care)
2. Funding body for complex needs should be part of decision making
3. EHCPs not necessary to get support from Adult Social Care
4. More able children/young adults need more support, peer groups
5. Not many choices for young people with mental health problems

Appendix 2: Social Care Table Feedback

Social Care: Transitions continued

Transition Planning and Pathways

1. Good to have a map/flow chart of what should happen at transition points so parents know what should be happening at each stage
2. Educational pathways are not made clear to parents
3. Peer support groups might be helpful to encourage younger ones to follow certain pathways

Early Intervention and Prevention

1. Help needs to come before the crisis - one parent considered putting child into care but was only a change of provision that was needed

Collaboration Between Services

1. Children's and adults social care provision - there seems to be a lack of knowledge between the services in order to signpost families towards the right provision or social worker
2. An outreach social worker would be helpful to help children who are struggling with direction after school

Appendix 3: Health Table Feedback

Health: Communication

Communication Clarity and Accessibility

1. Communication about CAMHS services and their functionalities.
2. Clarification of available support services and resources.
3. Information on transitions, especially to adult mental health teams.
4. Confusion regarding health services, including CAMHS, LD CAMHS, and community services.
5. Need for a single point of contact for parents.
6. Communication about waiting lists, waiting times, and diagnoses.

Collaboration and Coordination

1. Commissioned services to link health, social care, and education for better signposting.
2. Issues with communication between CAMHS, SEND team, and other relevant services.
3. Lack of attendance or reports from health services at EHCP annual reviews.
4. Disconnect between education and health sectors.
5. Need for child and young person-centered decisions and involvement.

Technological Solutions

1. Centralised app or website for child records to improve accessibility and sharing across services.
2. Challenges with existing systems like Egress, user-friendliness, and compatibility.
3. Text reminders and their effectiveness, especially when not naming patients.

Professional Awareness and Sensitivity

1. Consideration of appropriate communication methods, especially for children and those with specific needs.
2. Awareness of barriers to advocacy for parents who may struggle with coordination or access.
3. Equity in services and support, including consideration of access issues like language barriers or literacy levels.

Support Post-Diagnosis

1. Availability of support options post-diagnosis, including community support programs and educational sessions for parents

Appendix 3: Health Table Feedback

Health: Access to Services

Healthcare Access and Provision

1. Large estates being built with no new health services
2. Sensible transport to healthcare for people who live rurally or don't drive
3. No access to appropriate dentists
4. Challenges around access to continuing healthcare
5. Access to care agencies - challenging for limited hours, companies pick and choose
6. Children out of schools as cannot get a healthcare professional to support travel/care
7. Access to assessments for Autism/ADHD is taking too long
8. All health staff including administration staff must have training around ARFID and PDA - the lack of knowledge and understanding of these conditions is alarming and has a massive impact on the child/young person accessing any treatments/interventions.

Communication and Coordination

1. Single point of contact
2. Outreach to rural communities - lots of hidden rural poverty
3. Understanding pathways
4. Stop sending things by post
5. Cliff edge between adult and children's services
6. Lack of long-term advocacy for families
7. Desensitising in the system
8. No single point of access
9. Consolidating networks that can empower
10. IT systems not interoperable - why can't we have QR ones that enable this
11. Digital poverty - need to think about people who are not digitally enabled
12. "Tell your story once" approach
13. Feedback loop = better communication

Appendix 3: Health Table Feedback

Health: Access to Services continued

Educational Support and Access

1. School nurse in the school - not just for vaccinations/immunisations
2. School nurses to offer emotional support
3. Complexity is not acknowledged
4. Parents going into poverty to access private healthcare
5. Educational Psychologist assessed for dyslexia but didn't look at the possible ADHD symptoms
6. Parents not taken seriously - toxic positivity from school staff
7. School are main contact but won't do anything without a diagnosis
8. Lifelong Voluntary and community service advocacy
9. Access to special school - don't know how to access this, what is the process
10. Delays and more delays to get right school to get right support
11. Early years team - need to know what services are available
12. Community Pads prioritised private diagnosis
13. Nursery identified need, not picked up in COVID due to health visitors not visiting
14. No clear pathway from community paediatrics
15. No sensory processing disorder commissioned service - NOT OT
16. The term "Local Offer" isn't clear what this is or what it means
17. Who has a holistic view of my child?
18. Need someone to case manage neurodivergent children - missing service
19. Need to recognise ND - need to be able to identify and refer
20. Universal services starting a 4-year check
21. Institutionalising good practice - consistency resourcing, retaining capability and standard services

Professional Training and Awareness

1. Mental health "first aid" training
2. Challenges around training for Autism for health professionals/GP's
3. Teachers of the deaf - model for Autistic children
4. Better NHS recruitment campaign for therapies need to do more to encourage people to train

Appendix 3: Health Table Feedback

Health: Transitions

Transparency and Accessibility

1. Improve transparency about services and processes at different ages.
2. Create clearer pathways, such as an accessible advice team, to help families navigate services.
3. Establish clear discharge plans from hospital to school, especially for children without an EHCP or community nurse, to facilitate their return to school.
4. Address the gap between CAMHS and AMHT, ensuring suitable services for 18-year-olds with specific needs. Harmonize criteria and prevent parents from having to fight for appropriate care.
5. Increase transparency about age criteria for mental health services (16, 18, 19) to make navigation easier.
6. Ensure hospital schools receive sufficient information from health professionals.
7. Reduce delayed discharges at the Highfield Unit.
8. Identify key contacts in schools and ensure timely follow-up by medical contacts.
9. Clarify who supports children with health needs in school if not known to the CCN team, e.g., School Health Nurses.
10. Define accountability for children discharged from hospital to prevent parents from acting as coordinators.
11. Adapt support systems for 18-year-olds with developmental delays, recognizing their developmental age.
12. Improve information about processes and services from age 18, especially regarding legal responsibilities.
13. Educate healthcare professionals on LPAs for young adults with developmental delays to prevent barriers in accessing support.
14. Ensure carers are consulted in adult settings to avoid information gaps and support both patients and carers.
15. Enhance professionals' knowledge of each other's services to reduce inappropriate referrals and improve communication.
16. Ensure CAMHS paperwork and needed actions are followed up by AMHT.
17. Provide alternatives to calling 999 or visiting A&E when AMHT fails to respond.
18. Streamline specialist dental teams' access to medical records to prevent parents from repeatedly providing information.

Integrated Approach to Transition and Support

1. Transition to adulthood should involve an integrated, multi-agency approach (health, education, social care) with longer lead times, learning from new approaches in social care.
2. Establish a community paediatric consultant equivalent for adults with LD and complex needs.
3. Ensure all services, including GP surgeries, clearly identify and recognize advocates and (Lasting Power of Attorney) LPA nominees for patients, preventing carers from facing barriers.
4. Provide a support point for parents/carers, available day and night.
5. Develop comprehensive transition plans that smooth pathways, involve appropriate professionals (multi-agency), manage expectations, and reduce fears about losing access to services.

Appendix 3: Health Table Feedback

Health: Transitions continued

Challenges in Mental Health Services Transition

1. Provision Gap: CAMHS discharges at 18 often leave young adults without suitable support from AMHT due to differing criteria, creating a battle for parents and a sense of political manoeuvring.
2. Information Needs: Hospital schools require more information from health professionals to support transitions.
3. Delayed Discharges: There are discharge delays at Highfield Unit.
4. Key Contacts: Schools need key medical contacts who can promptly follow processes, which often take too long.
5. Health Support in Schools: Clarify who supports children with health needs in school if not known to the CCN team, such as School Health Nurses, especially after CAMHS discharge.
6. Accountability: Define accountability for a child's care after hospital discharge to prevent parents from becoming default coordinators.
7. Developmental Support: The system is ill-equipped to support those developmentally below 18, despite chronological age, especially after CAMHS to AMHT transitions.
8. Service Information: Increase awareness of processes and services for those turning 18, especially regarding legal responsibilities without LPAs.
9. LPA (Lasting Powers of Attorney) Guidance: Improve health professionals' understanding of LPAs for young adults with developmental delays to prevent access barriers.
10. Carer Consultation: Ensure carers are involved and consulted in adult settings to avoid information gaps and justifying their presence.
11. Carer Support: Provide accessible support for carers post-18, ensuring continuous support for both patients and carers.
12. Professional Knowledge: Enhance inter-professional awareness to reduce rejected referrals and improve communication, relieving the burden on parents/carers.
13. Paperwork Transfer: Ensure actions identified by CAMHS are picked up by AMHT to avoid gaps in care.
14. Emergency Options: Provide alternatives to calling 999 or visiting A&E when AMHT fails to respond.
15. Dental Information Sharing: Streamline access to patient medical records for specialist dental teams to reduce repetitive information requests from parents.

Support for Carers and Advocates

1. Need for support point for parents/carers
2. Carers face barriers accessing support
3. Professionals should clearly identify and know advocates and LPA nominees for a patient

Training, Communication, and Consistency

1. CAMHS to AMHT Handover: Paperwork and identified actions remain with CAMHS and are not transferred to AMHT, leading to gaps in care continuity.
2. Emergency Options: Lack of response from AMHT leaves calling 999 or going to A&E as the only alternatives.
3. Specialist Dental Teams: Parents repeatedly provide full medical histories at each appointment due to lack of access to patient medical records by dental teams. This results in wasted time and effort.
4. Knowledge of Services: Professionals often lack sufficient knowledge about each other's services, causing inappropriate referrals and placing the burden on parents to correct these errors. Enhanced training and improved communication are needed to address this issue.

Appendix 3: Health Table Feedback

Health: Transitions continued

Access to Specialised Services and Support

1. Adult Community Paediatric Consultant: Need for an equivalent consultant for adults with learning disabilities (LD) and complex needs.
2. Specialist Dental Teams: Reduce repetitive medical history requests by providing dental teams with access to patient medical records to save time and effort for parent carers.
3. Sleep Management: Address sleep issues for those with ADHD/Autism.
4. Awareness of Services: Improve general awareness of available services and support.
5. Consistency in Diagnosis: Ensure consistent practices in diagnosing learning disabilities versus Autism/ADHD.

Improvement Opportunities

1. Transparency: Improve clarity on what happens when and who is involved.
2. Access and Coordination: Create clear entry points for families to find services and join the dots. Improve discharge plans from hospitals to schools to prevent delays in children returning to school.
3. CAMHS to AMHT Transition: Address gaps between Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Teams (AMHT). Harmonize criteria and reduce parent advocacy burden.
4. Hospital to School Transition: Ensure smoother return to school post-hospital admission with better-coordinated plans and information sharing from health professionals.
5. Delayed Discharges: Address delayed discharges at Highfield Unit.
6. School Contacts: Identify key medical and school contacts, and streamline processes to avoid long delays.
7. Support in Schools: Clarify who supports children with health needs in schools if not known to GCN team, and determine key contact post-CAMHS discharge.
8. Accountability: Define accountability for children post-hospital discharge, often falling on parents as coordinators.
9. Developmental Needs: Support for individuals transitioning from CAMHS to AMHT must align with their developmental, not just chronological, age.
10. Information on Services: Improve information on processes and access to services from age 18, including legal and financial responsibilities.
11. LPA Understanding: Address gaps in health professionals' understanding of Lasting Power of Attorney (LPA) for young adults with developmental delays.
12. Carer Involvement: Ensure carers are included in conversations and decisions in adult settings to prevent information gaps.
13. Carer Support: Provide continuous support and communication channels for carers, especially as their young person transitions to adult services.