Feedback From Families – Autumn Term 2024

Overall Themes for the Term:

- **SEND Team communications**
- **Concerns over changes to ADHD & Autism referral pathways**
- **More information needed for parents**
- **Post 16 – transport concerns, lack of provision and more information needed**
- **More special school places and more inclusive mainstreams are needed**
- **Mental health support – more needed and clarity over what is available where and to whom**
- **Growing need for support for ADHD**
- **More information for families on Alternative Provision (AP)**
- **Complaints upheld but nothing changes (SEND team)**

Local Offer Live 24 – October 12th

Feedback collected from families attending on the day

What's going well:

- This whole event
- This event is so helpful. All the people I want to see under the same roof.
- ASSIST - they were a huge help
- Have found new information and teams in Wokingham that I'd not known about until coming here today.
- SENDIASS are amazing
- This event is great. Did not know any of the great information until today.
- it's really good

What could be improved:

- More info for parents regarding starting SEN schools. How it works with EHCP process
- Not enough activities for post 25years. We need a Local Offer event for 25+years
- Tell parents about teams and services so we can help our children
- Transport for 16+ special schools
- More inclusion in mainstream schools
- We need more special schools like Addington. My son needs a special school in EHCP but no space anywhere (2 people commented on this)
- Lego here next year
- Communication between parents and Disabled Children's Team

- ADHD medication pathway - too long!
- EHCP process
- Communication! No one is available to take calls and emails go unanswered. Why is this allowed to happen? Does nobody manage this team?!
- Alternative provision information
- Post 16 with an EHCP
- Understanding in school and local services for ALL SEND. My son's school have not attempted to understand his needs and despite offering info on training, they have not taken any
- Listening to our journey
- Support for understanding and sharing knowledge of Ordinarily Available and Graduated Response for parents

What really matters:

- Get the paperwork right! and be responsive on calls and emails
- Friends
- Child's voice
- Holiday provision in the summer
- No Idea who our case officer is
- Post 16 places locally and transport. No buses to ever get to the places
- respite/short breaks provision
- Be kind
- Talk to parents. Be honest and have conversations
- Special schools and therapies for speech and communication
- It would be good to have responsive case officers
- Transport re Over 16's

SEND Update for Families with WBC & Health (via Zoom) - 23rd October

Full slides and Q&A document available on our website: SEND Update for Families with WBC & Health 23rd October 2024

Themes:

- SEND Team communications
- Improve internal (WBC) communications between different services
- Mental health support - more information needed about MHST and MAIC, concerns over waiting lists and being moved from one waiting list to another
- Concerns over changes to ADHD & Autism referrals

SENDIASS Drop-in's

(SVW attend to chat with parents and gather feedback/signpost whilst parents waiting to see SENDIASS). Total attendees Autumn Term = 29

Comments from those attending the drop-ins:

September

- All attendees interested in knowing more about how to find information. Spending a lot of time searching the internet but know sure what for.
- parents of child in year 5 concerned about phase transfer - do not know what schools to look at - no guidance - feel alone in search for next setting

October

- Parents receiving letters advising 'No to Assess', are seeing this as a paper exercise. No interest in clarifying information they receive or initial observation of child. Adds delays and stress for the child/family.
- Questions raised over SEND Team processes. Are there any written processes? Are they checked that they have been followed? Why is paperwork sent out with incomplete or inaccurate information? Where is the quality check?
- Child now in year 10 was on pathway for 2 years but didn't receive information for PFA (When is this process triggered and what checks are made to see that family have all the information needed for PFA)
- Family of child with specific learning disability were told no one in school aware of how to help child. No one from school researched or went on any courses to find out how to help. Why?

November

- Parent asked if there are stats on how many EHCP's are school led vs parent led as they had experience of school are not supporting requests
- Parent of child out of school for more than a year are not getting support to get child back in with reasonable adjustments – school just say that child can't cope
- What social activities are available to a child with SEN and how to find info

December

- Help finding more information from local websites for help relating to specific learning disability (mutism) needed

Parent Carer Participation Groups

Parents attending: 5 in two face-to-face meeting, 13th November

Priority areas for improvement: User testing for Local Offer Website. We ran 2 face-to-face sessions this term with the WBC Local Offer Coordinator focusing on the information about schools on the WBC Local Offer website.

Findings and suggestions from the Parent Carer Participation Group informed the Local Offer workgroup to help improve services**.** Key findings were:

- All the families struggled to navigate the Local Offer website to find the information.
- Directory listings are too wordy and inaccessible.
- information is out of date.
- Information doesn't feel comprehensive and there needs to be links to provision beyond Wokingham.
- Differing information on main WBC site and the Directory.

Review of other LA websites gave recommendations for Local Offer Coordinator of areas to make improvements on the WBC website and improve user experience.

SENDIASS Training courses

EHCP Annual Reviews Process - 23rd September (13 parents attended)

- Parent unable to get a response from Senco, Head Teacher, Governor or SEND team to book an annual review
- Child had A/R in Nov 23 it was not finalised but sent to parent. Working towards 2024 A/R now but based on pre–Nov 23 as this was not actually issued/finalised.
- Parent has never seen any IEP or smart targets from school for their child
- Who carries out A/R is with when YP is in apprenticeship (post 16)?
- 2 questions on allocation of personal budgets and what can be asked for within specialist settings
- Concern for child at phase transfer to secondary - Primary support is working well but unsure of how/what support is available in secondary and if YP can cope or need EHCP tightened up

EHCP Process – 3rd October (7 parents attended)

- 2 families said that School Senco didn't support their request to apply for EHCP (academically at expected age, not seeing adverse behaviours in school etc, but behaviours happening at home. Both will be submitting parental EHCP requests.
- 2 families have YP moving into post 16 setting, now seeing need to apply for EHCP but with new setting having no current knowledge of YP. EHCP request being made by parents.
- What should school be documenting and sharing when child is out of class - Is there a standard/suggested logging by school/Senco?
- Parents wish they'd had this information months ago instead of finding out accidently via social media (about the course)
- Concerns over No to Assess letter – families to go through mediation, but concerned that tribunal dates now Oct 25

SEND Support in School & Effective Communication – 19th November (8 parents attended)

- Are there guidelines for frequency of meetings with Senco and visibility of SEN plans (child does not have an EHCP)
- Schools are not proactive in organising and planning meetings or interventions (3 parents fed this back)
- You get “wishy washy” explanations and responses to requests. Keep getting “brushed off”
- Schools are not signposting parents to available training from Sendiass and would be helpful to have known about Parent Carer Forum SEND Voices Wokingham sooner (from 5 parents)
- School asked parent to submit request for EHCP and they would add their input when asked
- Information needed about who’s duty is it to put child on SEN register
- What is the “Assess, Plan, Do, Review” process? Should it be shared with parents as parents had not seen any evidence of this

Coffee Evening /Drop-in & Chat, 17th September & 19th November

13 families attended (this new drop-in)

What’s going well:

- Brilliant charities - CLASP, Me2
- Optalis are good for day center /activities

What can be improved

- Searching for schools and what provision they offer. Any restrictions they may have e.g. being 3 years behind academically or will take ASD but not with ADHD
- Directory of Special Needs Colleges / courses - The Activate Learning etc websites are so orientated to academic/vocational mainstream courses. Hard to find SEN stuff.
- SEN aware counselling - child went to ARC for 12 sessions and he has no idea what they discussed. Parental feedback and even input is not permitted
- Support education beyond 25. Some SEN's mature much later
- Support for parents of children with ADHD

Coffee Morning/Drop-in & Chat - November

Attendance – 3 families attended

- Concerns about the process and quality checks when issuing A/R paperwork. Amended EHCP took 7 months to be sent. What family received was “absolute rubbish with so many omissions especially critical health. Didn’t mention dietary intolerance or that child has seizures”. SEN Case worker didn’t turn up to A/R when they were expected
- Clarity is needed over EOTAS when child has been out of school for over 1 year.

SEND Team Drop-in, 5th December

- EOTAS –No support for families, we have to manage everything and just fall through the gaps. Is there a local EOTAS parent support group?
- Is there a list of approved AP providers and can parents approach AP directly? What do the different AP’s offer hours/full day?
- Are there any AP’s that do more vocational activities?
- Are there hard copies of the PfA Guide available. The online version is hard to use.

General Questions / Comments Autumn Term ‘24

General feedback and themes via email and social media

SEND Team Communications/Complaints process

- SEND Team email boxes closed without auto responses of where to redirect emails to. Families left for 2 weeks without a response and then told that email box was no longer monitored.
- Parents unclear on panel process, things not happening in a timely manner and no communication when dates change.

- School unaware of SEND team email changes, parents having to update school
- SEND team officer still giving out closed email box addresses when notification has gone out from SEND team that they are no longer in use.
- I’m writing this to you but copying in others as the communication in the SEND team has been terrible for a long time now and I feel that the only way to get a response is to involve people higher up sadly. I have been waiting for an urgent reply but no one responds.
- Dissatisfaction with the Local Authority’s (LA) handling of my son’s case, particularly with regard to its failure to meet agreed deadlines, provide timely and adequate communication, and fulfil its statutory obligations toward disabled children. The LA’s apparent neglect has directly impacted my son’s ability to receive the educational support he desperately needs and is legally entitled to.
- Made a complaint in January - it was upheld but nothing changed, and no action was taken - I made a stage two complaint which was also upheld with a slight change then all person dealing with my childs case left and now we are back to square one.
- I had a meeting with Jamie Conran in February who promised everything would change and that he was involved now…..never heard from him again and hasn’t responded to a single email since…
- We have a complaint that was upheld by LGO but nothing with WBC has changed.
- I have just emailed my case worker regarding our phase transfer and have received an out of office to say she’s left!!!!!
- Just a little update. It’s now been 6 weeks, 8 emails, one complaint and the only person I’ve spoken to is Julie who responded to my complaint. Even she can’t get anyone to respond to me. A promise to call me has failed again today and two emails not replied to today when chasing the call. So, I’m not waiting for someone to get around to it. I’ve now complained to our local councillors (all 3), our MP, director of children’s services and head of SEN. OFSTED will be next. They have a job to do, by law, and they are failing us and our children.
- I got my child’s draft EHCP on 30th October, been told I should have received his finalised EHCP within 15 days but still nothing. School also has nothing
- Is anyone still having issues with communication or lack of communication from Wokingham SEND team? We have followed the advice around the communication promise and for 4 weeks we’ve had no response. We’ve phoned, messages have been left and passed on, yet still no response. How does anyone get a response from the SEND team?
- How do you make a complaint about SEND services at WBC? It is to do with the ehcp assessment process?
- In the exactly 2 months since my case officer left, I'm now on case officer number 3 since then! This worries me and I'd like to understand more about the restructuring, staff numbers, what work is being done to get feedback about the staff turnover, any retention incentives etc? No idea what is going on inside the department, but I'd love to know how

many members of staff they have now, how many they'll have when all places filled, will they be permanent? Also any way we can find out how the staffing compares to other boroughs? I've worked with other LAs and just feels like Wokingham have a bigger issue than others.

- SEND COMMUNICATION - can't remember how many months ago this was a big thing and there was a whole project and was all going to be positive, might even have been last year?! Anyway, I'm not seeing a great improvement (although I'm lucky and my current case officer is quite responsive but in general I think it's still an issue).

Support at School

- School not making reasonable adjustments for young people which is affecting their education (uniform change recommended by consultant)
- School blamed parent (as child well behaved at school/melt down at home), wouldn’t make reasonable adjustments. Formal diagnosis sought to prove to school that there was a need
- Senior school made reasonable adjustments to uniform (top, shoes and jumper) when requested
- Too many children receiving no education at all and been left at home with nothing in place. Yet parents would be in huge trouble if they let their child just stay off school!

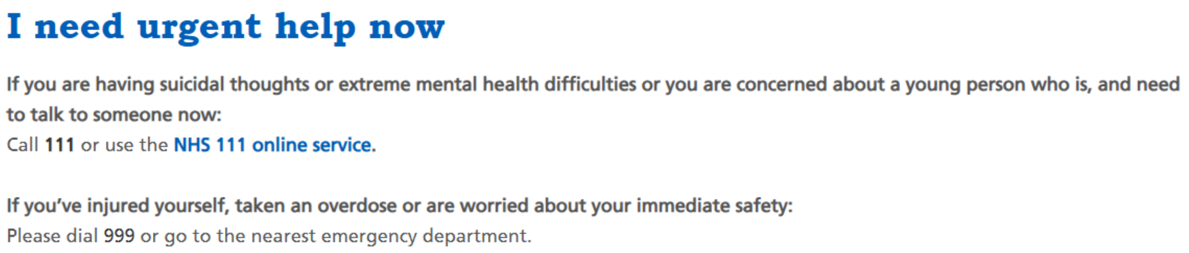
EHCP/Annual Review Process

- I’m fighting hard to get an EHCP for my child currently. What i have noticed is with Wokingham LA is that although they can send out emails or letters declining to issue they seem to be the same wording each time eg although we recognise that your child has SEN needs these can be met under the already available 20 hours funding which schools receive. (something like that is how it goes). They fail to explain where the holes are in any evidence you submit or tell you what’s needed for you to secure an EHCP.
  X has so much evidence of their struggles in school and is on a part time timetable. I’ve been fighting the LA since end of Feb and getting nowhere. They never told me that X provision map from school showed nothing and wasn’t worth sending to them. It should have been filled out properly showing Xs needs and struggles. So many kids are being failed.
- So Wokingham SEND team have a new type of annual review. A ‘monitoring annual review’ that takes place when an AR is due and have an active tribunal. It will always result in a no to amend and will not inform the tribunal process or working document. I don’t think they have read the SEND regs, law or understand a statutory process. I just despair with the whole situation!

- SEND Panel outcomes taking too long to get back to families, several times I've also seen totally inappropriate paperwork submitted to panel causing cases to have to be represented to panel sometimes on several occasions, all causing further delays

Mental Health Service

- The crisis number has changed (a week before), however when the family spoke to someone at CAMHS they were given the wrong (old) number. They are not sure if the number on the BHFT is the correct one or not.
- What should a family do instead of taking child to A&E? The family spoke to 111 and they advised going to A&E. Website also says to go to A&E if worried about immediate safety, so website is confusing for families.



I need urgent help now

If you are having suicidal thoughts or extreme mental health difficulties or you are concerned about a young person who is, and need to talk to someone now:
Call **111** or use the **NHS 111 online service.**

If you've injured yourself, taken an overdose or are worried about your immediate safety:
Please dial **999** or go to the nearest emergency department.

- On call CAMHS rapid response came to see child/family at hospital (Friday night) spoke to them and left. Child was still suicidal, but on call CAMHS rapid response person would not respond again. Staff in hospital told family "that on call person always switches their phone off when they are on call and goes to bed, she won't come back". Family said nothing happens at weekends, you have to wait until Monday.

Social Care/CWD

- Is there any information on certain processes and timescales? We have regular CIN meetings but have not had any minutes for so so long (probably not all year), used to always have someone in the meetings doing the minutes. Minutes are not just a nice to have, they can be vital and make a huge difference to families who have challenging situations with that department! If you happen to have any links to any processes, I'd really appreciate the info.
- Carers Assessments - I think we have a big issue with these, certainly under CWD team anyway.
- Short Breaks - I've had a nightmare with my situation and confusion over what money can be spent on. When I have the time to submit a complaint about this

Therapies

- I'm livid!! I've been waiting 6 months for my child to have a referral to OT because of their eating disorder and sensory processing… finally get an appointment it's a flipping webinar on YouTube…. What the hell is going on with the NHS? I guess we are going to have to go privately once again to get my child's needs met. My child needs proper OT with lots of in person support.
- Letter from OT service - one paragraph saying my child would be kept on the waiting list. One saying they'd need re referring to be seen and a third paragraph saying wait for a telephone consultation. Guessing they were meant to delete one of them? But which one?

Transport

- We were sent an email at the beginning of August and a follow-up text today informing us that a company called Alanis Travel would be taking over the taxi run. We have tried to contact them but no response and so we don't know the pick-up time. Not particularly impressive for children with autism/ADHD. We have also spoke with CTU by phone but no joy and so we have an extremely anxious child and no information we can give him to ease his anxiety. It would have made sense for the taxi company to be in touch in advance for children with additional needs and so we worry that they may not have the necessary skills and knowledge to transport such children.
- Just fed up of the battles, inconsistency, discrimination and the fact I raised these issues 3 months ago and today was the first time anyone has spoken to me about the issues and even then SEND transport could not or would not answer mu questions.
- Concerns raised over £5000 cap for PTB for school age children.
- Parents require more clarity over the information required for mileage/petrol claims, what is the information actually required eg attendance report from school etc.

SENDIASS

- The policy for requesting case notes from SENDIASS is unclear for families. Policy states it can be requested by email, however when information requested family advised to complete WBC data access route.

Neurodiversity Pathway

- While we had an 18 month wait for the ADHD assessment since the assessment took place the ADHD team have been amazing. From the time of the assessment appointments and diagnosis the ADHD nurse has been supportive, helpful and so responsive. My youngest received his ADHD diagnosis 6 weeks ago and this week he has started medication. I’m not sure if this is normal in terms of time frames as I thought the wait would be longer. The psychiatrist we saw at the medication appointment was kind and gentle and spoke to my son rather than me which is how it should be. Just wanted to share what a positive experience we’ve had if CAMHS and some of the staff.

- Gaps in service - it really feels that there should also be something similar for those children (who mask at school and then have behavioral issues at home) and their families with ADHD who may or may not also have a dual diagnosis? Is this something that could be considered in the future? I know they are also campaigning for this in Windsor and Maidenhead

Changes to Autism & ADHD Referral Process

Sounds like Berkshire Healthcare have been speaking with the EHCP gate keepers at the LA when they came up with these ideas 🙄 how is adding 6 months/2 terms of plan/do/review before a referral is 'allowed' to proceed to a 2-year waiting list helpful?

The idea to move referrals for diagnosis towards schools and only after 6 months of intervention is unlawful. School staff are not medically trained and miss signs, symptoms and opportunities to address needs. Many of our children are not in school because their needs are not being met. A professional diagnosis is important for many reasons. The diagnosis can validate an individual; they can begin to understand themselves in terms of the diagnosis. It may help them understand why they are themselves and why they feel different to others - knowing this is a diagnosis can help them to understand it's not their fault. The diagnosis may help them to access strategies to help them manage themselves, and gain support, encouragement, empowerment etc and this may improve their self-esteem and confidence. Unfortunately, a professional diagnosis is sometimes essential in unlocking the adjustments and individual needs and support. The diagnosis unlocks accessibility for individuals to help make the world and environmental more accessible to them, rather than trying to live in a world that is not setup to meet their needs. It's certainly my own experience that my child's school, for example, will limit the support they provide unless they have medical evidence and even worse, they need an EHCP in place before we're listened to as parents. Another reason is that it provides legal support for the individual. They are covered under the Equality Act 2010, which provides legal protection for disabled people and Autism Act of 2009. The Autism Act aims to reduce inequalities, provide diagnosis and support training and guidance to service providers, improving access and raising awareness. I honestly think we should all start a petition and some legal action against them. This is not the way to address the funding and resource issues within SEND.

I'm in utter shock, I'm so angry about this. It doesn't affect me as all 3 have their diagnoses but I have so many thoughts on this.

1.Had this been done with any consulting with families/schools etc? It may be just that I've ignored too many emails/posts but don't want to assume that's the case as it may not be just me as i know how rubbish co-production/consultations can be!!
2.Am I missing the point or is this all about school aged children? What about those younger children? Obviously there was always a barrier to the ADHD assessments so they'd be school aged but Dingley was for all the ASD under 5s and I can't see what's going to happen with this age group? Not compulsory to have a nursery/pre-school etc. so what about those children who may normally be referred as a toddler etc?
3.If they are changing this, will they remove the barrier of waiting until a child's 6th birthday before they can be referred? I can bring up the NICE guidelines again as I did years ago! What about those who don't get the support because the difficulties are so much that either the child doesn't attend full stop or a support plan is put in place but the child has such significant difficulties before they've done that period of time expected that they either school refuse or gets excluded? What about the damage the child whilst tick box exercises are carried out? This simply won't work for all!
4.I'm so done with hearing that a diagnosis isn't needed and makes not much difference. It actually makes ALL the difference if it's a case of a child needing an ASD school, for example. Are all schools now going to legally have to stop having blanket requirements to have an ASD diagnosis to go to an ASD specific school?!
5.Sorry, ranting, definitely will have more to say on this but I'm stepping away for now. Thanks for sharing the info, much appreciated and please do feedback my thoughts on this.

Thank you for sharing (on another post) the update which states this policy won't be implemented until January, as there was not a proper consultation period.

It looks like parents have to voice concern to the child's setting to ask for help via a support plan, and if they still need more help 6 months after that, the setting can make a referral for assessment.

What if the setting doesn't put any support plan in place, for a myriad of reasons?
This is an attempt to lower the number of people making requests for assessments and is disgusting.

If a child does "manage" with the support plan, or appears to, but they are autistic, what is their route to diagnosis? Aren't they entitled to understand who are they, and learn about themselves? I know the intention is to get the support in place regardless of a diagnosis. That should be happening already, but isn't, in many cases.

I understand that an Equality Impact Assessment should be carried out. Could you please ask if this could be shared with parents?

This should identify whether the policy puts protected groups at a disadvantage. Children who don't attend settings, or who mask at school, or who attend schools that do not recognise traits and put it down to "bad behavior", will surely be at a huge disadvantage.

Neurodivergent children will later be neurodivergent adults. If local policy discourages seeking diagnosis, those individuals will not be able to access support which they are legally entitled to, reaching transition services and into social care.

I also noticed that the policy goes against the Government's national strategy for autistic children, young people and adults:

"Receiving a timely autism diagnosis is vital in getting the right support and helping autistic people and those supporting them to better understand their needs."

And "It is widely recognised that children and young people should be identified as autistic as early on in life as possible, as this is important in ensuring children have the right support in school and as they transition into adulthood. However, evidence from the National Autistic Society shows that many, in particular girls, are not diagnosed until adolescence or adulthood because the signs are not recognised."

I find the changes made to the ADHD/ASC assessment referral process made on the 1st November extremely concerning. Clearly change is essential given the long waiting times for assessment. Clearly support plans are a laudable aim and every parent would agree that needs need to be met early. We hope it would increase the chances of c & yp's needs being met early. I recognise that it sits within a national plan announced by Rachel de Souza but where is the school funding or school training which would be essential?
This change feels like it risks delays and requires failure of support prior to referral. It feels like a higher bar needs to be met to reach ASC/ADHD referral than for an EHCNA now. Presumably more parents will feel they have no options except to apply for an EHCNA to gain evidence of needing an ASC/ADHD assessment and reaching an EP? This feels like a new delay which risks deepening the gulf into which c&yp can fall due entirely to lack of funding to support c&yp. The change requires schoosl to actively engage with parents without acknowledging how hard it can be to secure this.
I cringe at raising criticism; teachers are amazing, no teacher can possibly be comfortable working in the current underfunded, over-pressured results-driven environment. It is the lack of funding of the entire system which isn't allowing some c&yp to flourish, not teachers or CAMHS staff themselves.
Engaged, academic, committed, polite parents desperately try to work with school but cannot access support for their young people to remain at school or in any educational provision and can't access sufficient c&yp mental health support early enough. It can be hard to access mental

health support even when c&yp are in crisis. Parents are left picking up the pieces with minimal professional support.

Unfortunately, in our experience, young people aren’t blank slates who are always able to engage with professionals involved in their education or care if needs haven’t been met early. Young people who have experienced bullying, whose challenges haven’t been fully seen or explored at school, who have felt significant overwhelm and sensory overload risk facing increased vulnerability when they just aren’t able to fully engage with unknown professionals subsequently. We had to work very very hard over many months to help our young person be able to re-engage with professionals after becoming unable to attend school. We had to find and fund private therapy and private paediatric treatment before one of our young people could engage with CAMHS. Young people aren’t necessarily able to try another school after an initial unsuccessful placement in our experience. This is devastating. But understandable. Breaking the cycle of anxiety is so so hard; early support is essential.

Joint Working

This referral change could only work if there is a new agreement between CYPFS and schools on how to meet c&yp's needs in education, new neurodiversity training for teachers (especially on anxiety, attendance and trauma) and there is new funding for it.

Has there been a significant policy change whereby it is now agreed that autism and ADHD can be treated as SEN, with funding for the provision? How can parents find out which schools do support ASC/ADHD? How can parents find neuro-affirmative schools?

As a parent, I found significant inconsistency between school staff in the understanding of autism. One teacher was so insightful & asked about possible challenges shown in my yp’s work. When we discussed the possibility of autism and his experience of school, she explained that she had personal insight and now knew exactly how to support him. I was immensely grateful to her, she had a fantastic teacher-student relationship with my yp and I think of her with gratitude a few years later. Unfortunately, she didn’t teach a core subject & my young person didn’t have classes with her for long.

This positive experience of insight into autism was memorable as it wasn’t frequent. I shared information about my children with school, kept in touch, highlighted concerns, but it was like politely emailing into a void. I still worry that I contacted the wrong staff members? I didn’t see my contact filtered through to all class teachers, who didn’t all seem to know that my yp might be autistic and were having SEMH difficulties or perhaps instead weren’t aware of the impact these additional needs may have on their ability to access education specifically? One of my yp had good connections with some other staff members but their positive classroom connection and a great connection with the school nurse eventually, whilst essential, couldn’t counteract SEMH/SEN challenges.

Most recently, it felt like the number of temporary/cover teachers and the brutal workload for teachers meant I couldn’t identify a single member of staff who knew my youngest child well. No member of staff would have been able to make a support plan or decide whether to refer them as they just didn’t know them. Unsuccessful school transition prior to crisis meant their autism and ADHD assessments had to be undertaken without documentation completed by secondary school. Crisis can be reached within two terms. Due to the current pressures on schools, it did not feel like staff had sufficient training or scope to act in loco parentis for my yp during the school day.

As ADHD and autism assessments are medical assessments, it feels inappropriate for school staff to now undertake triage to determine which children and young people can proceed to medical assessment. I do not have any confidence that school staff would have had sufficient knowledge of my young people, training, enough staff, funding or time to triage my young people. School-completed ADHD forms submitted for private assessment were lacking in insight or understanding of my young person, completed by staff who hadn't taught our yp. Why? I couldn't see any value in school's input to my yp's ADHD assessment through their forms, except that it highlighted what an unsuitable environment it was and how they could not remain somewhere their needs were so unheard. When we received a post-assessment ADHD summary which was designed to be for school so school could provide support, whilst I would have sent it to the SENCo if my yp had still been able to attend, I was fully aware that there wasn't a single staff member who I could send it to who would have time and ADHD training to try the suggested modifications to support their education.

I am not aware of either of my yp ever having had a classroom observation undertaken; I don't imagine there is any resource for classroom observations. Where are the EPs who could help with new support plans? We've never seen an Educational Psychologist.

As my young people have become unable to access formal education due to neurodiversity and anxiety, as parents we are now responsible for their education, medications, referrals, assessments, follow up and facilitating access to services. This is the only way I can see their provision being managed. When we tried to seek shared care for medication, it was declined leaving me to scramble for a private prescription quickly. Everything is hard and expensive but at least I know where we are. If competing demands at home mean I have private SEN assessment referrals waiting for me to submit them, I can work on it. We did not have transparency at school. We understood we were waiting on a school waiting list for our yp to be seen by a specialist (unrelated to ASC or ADHD) only to find when we followed it up that the waiting list no longer existed.

We tried but failed to get one yp onto an ADHD assessment waiting list through school; we secured private assessment instead; there was no way my yp could wait years to be assessed. We were trying to enable our young person to remain in education, time was critical. Diagnosis came after having to leave school mid-year in crisis without a destination.

Diagnostic advice regarding school support from a private company via CAMHS differed from what the school could provide and was deemed incorrect at school; joint working is vital, and we haven’t found it consistent.

Are schools fully aware of support for autism being needs-led? Having made an autism assessment referral myself for one of my yp whilst they were at primary school, I didn’t pass the sheet which CAMHS sent me to pass on to school indicating that support should be needs-led to secondary school as my yp wasn’t at secondary school. It didn’t occur to me to do so as they weren’t yet at secondary school. Did this impact the support my yp received at secondary? Is this why my yp wasn’t eligible for more than minimal reasonable adjustments at secondary school, in spite of me communicating with secondary school about them being on an autism assessment waiting list, asking secondary school for support and secondary school receiving a full SEN handover from primary school? Do parents need to communicate SEN policy to schools? Is there no county-wide school provision for autism/ADHD or did this come in on the 1st November 2024? Will it look the same across schools? How can there be parity given academy schools? Are all schools now within MHST coverage?

Aside from some reasonable adjustments and some other input at school, support hasn't felt as if it were significantly needs-led or diagnosis-led (although most of my young people's diagnoses came after they became unable to continue at school). Parents must be told earlier if schools cannot provide SEN support for autism or ADHD.

In our family's experience, a six month delay to the referral process would just have meant our yp were further into crisis when assessed unless school provision has changed dramatically since my yp became unable to attend school. Diagnosis has not halted crises for either of my yp but has given them greater understanding of themselves by talking to professionals and has given us as parents an enormously deeper understanding of which areas we can try to scaffold (especially through private assessment and diagnosis).

I failed my young people by not knowing what it was that I didn't know. I didn't know to avoid burnout as I didn't know they were autistic and had ADHD. I didn't know how rates of PTSD may differ between autistic & neurotypical individuals and therefore the potential impact of negative experiences. I knew it was possible that one of my young people was autistic but I didn't fully understand the possible impact and was amazed by my yp's other eventual diagnoses. I wish I had understood about concurrent conditions sooner. I knew how much my young people were struggling but didn't know what the exact causes were. I sought professional insight but was hampered by the pandemic. I didn't know the risks of encouraging them to continue going to school in spite of EBSA because I didn't know what EBSA was. I didn't know that an EBSA policy didn't exist. I didn't know that the school staff I encouraged one to go to didn't have EBSA or neurodiversity insight & didn't recognise their behaviour as extreme anxiety. Only the assessment and diagnostic process alongside lots of looking for information allowed me to understand what my young people were experiencing and how to support them. I read everything I can and attend every training course or webinar that I can but I needed to know what we were dealing with and to have talked about my yp specifically with assessors to know what to target. Writing referrals myself, writing detailed developmental histories for my yp's ADHD and autism assessments consolidated my understanding of their traits.
Assessment and diagnosis has allowed my young people to have a vocabulary to further explore and explain their own experiences, to discuss their needs and has allowed me to better meet their needs.
For example, we had plenty of 'learning to tell the time' resources at home, early learning clocks, digital and analogue clocks and used visual time planning for busy times. I couldn't understand my yps' difficulties with telling the time or time management and worried about this ahead of one yp's GCSE exams, but it was only after both of my teenagers' ADHD assessments and extra training courses, I really understood time agnosia and challenges with executive function. I am looking now at how I can scaffold this. In short, I couldn't find strategies to help without knowing which traits most applied to them, in spite of having been to many parenting webinars/parenting courses. My yp is already a young adult, it is far far too late.
Assessments where professionals really pinned down my yp's strengths and challenges have been invaluable. I spend so much time with my yp and we have so many characteristics in common, I couldn't see with clarity some points which only assessors were able to highlight.
The assessment & diagnosis process has given my young people the vocabulary to talk to each other and find new common ground; they have built a strong relationship and now sometimes

step in to support each other when they recognise their sibling is finding something hard. This is revelatory.

Time is of the essence for yp's needs (exacerbated by the pandemic). If problems at school don't emerge until secondary school, the window of time to meet needs prior to crisis can be very tight, this move risks adding a delay and relies on a co-productive relationship.
We have completely missed any professional transition to adulthood preparation, meaning no SEN/SEMH informed careers advice or planning and the impact is stark. One of our young people has been unable to move into employment, training or College. This was avoidable. It feels like an EHCP can only help if you could see that the yp's needs wouldn't be met and would increase in the future.

Support Plan
The new support plan could only be beneficial if school have the resources to engage with parents to provide support for yp. In our experience, school would not have had enough funding, training or time to be able to fulfil a support plan at all, especially not in relation to insights into anxiety and neurodiversity, attendance support or autism and trauma. Within school, we found a gap between the SEN department and the attendance department; we needed signposting between them. Perhaps the support plan would work in some schools but I can't see it working universally unless there have been significant recent changes.
I cannot imagine how any interventions made through a support plan could remove the necessity for diagnosis of autism and ADHD.

Joint submission of referrals
In terms of how young people unable to attend school can access professionals, my young person in this category is above the age to have a health visitor, had needs too complex for the school nursing team, has only recently accessed Counselling, doesn’t have a SLT or an NHS pediatrician and I don't feel she is very well known by a CAMHS clinician although she has had CAMHS assessments. The only professional I can imagine would have been able to triage her ADHD assessment referral was the private pediatricians we found when already far into crisis. Private pediatricians have saved both of my yp (alongside a new CAMHS intervention for one yp after crisis). We were so so lucky to be able to find this private pediatric team after trying so many other private providers who were too full to take on new patients. We only found this pediatric team when already deep into crisis and only due to having a friend who had worked locally as a pediatrician and could make recommendations; presumably many other families in our situation wouldn’t be so lucky. If c&yp are just on waiting lists to see other professionals, support plans could take an infinite amount of time to put in place.
The difference made to one of my yp by being assessed, diagnosed and medicated for ADHD, (especially as private ADHD assessment triggered private treatment of poor sleep and coincided with a new CAMHS treatment) has been revelatory. Diagnosis and treatment (from CAMHS too) has increased their ability to manage everyday life. There is no way I would rely on another service to decide whether we could access this.
What is the change which will allow already stretched schools to provide support plans for c&yp?
Will EBSA support be put in place so all c&yp can access a support plan?
Why does it matter? /Risks

Diagnosis is vital to c&yp being assisted to achieve greater insight into how their brains work and diagnosis is vital for parents to be assisted to really see with clarity in which areas their cyp can benefit from scaffolding.

We have found to our disappointment that if needs aren't met very early, they can increase. CBT was accessed through multiple providers but it didn't work well for our yp at those moments and it took some time to have a full assessment to be able to access other treatments.

Some local providers made a difference to one of our yp. However, it felt like treating anxiety without having had ASC/ADHD assessments meant we were dealing with one part of a larger picture without knowing what the whole picture looked like. We were only able to see the full picture of SEN/SEMH needs when we knew that ASC and ADHD were definitely part of the picture. We would have benefited from ASC and ADHD assessments and diagnoses much sooner.

If a yp quickly becomes above school age without needs having been identified or met in time, their vulnerability can increase and they risk being unable access adult life. It feels like the future demand for adult social care can only explode.

This change to referral feels like another instance of one overwhelmed under-funded service signposting parents back towards another overwhelmed and under-funded organisation. Unless the situation at school with ordinarily available provision and EBSA support has changed significantly recently, surely this move will increase demand for parental submissions of EHCNAs? What else can parents do? There aren't unlimited opportunities for c&yp to just try other schools if needs haven't been met at the first; mental health can decline first. C&yp can become alienated and 'othered' and unable to just try again. When yp’s recovery from MH crisis has been hard won, why would families risk it by gambling on another educational setting maybe being able to meet their needs?

Parents have to be able to submit referrals; school and the GP are not routes. We have tried. Neither GPs nor schools have scope, parents are the only party with sufficient insight into c&yp's daily struggles and sufficient investment in searching for positive outcomes.

If one looks at the data on late-diagnosed or undiagnosed adults, the potential for poorer outcomes, can the referral process really be shifted to schools who are already overwhelmed?

I feel so regretful that my yp have encountered this moment in education provision; I have no doubt that at another moment in curriculum policy/another level of educational funding/different behaviour as a cohort of students, they would have been able to remain in formal education, would have very very good exam results and would have gone into higher and further education. Academic well-behaved c&yp are falling out of education due to the lack of a safety net; this change pretends there is a safety net whilst widening the gaps.

Feedback on SEND Drop-in Sessions with Jamie Conran/Sally Furness

11 with Jamie Conran (face-to-face) & 6 with Sally Furness (online)

Initial feedback from families was very positive, they were grateful for the opportunity to speak to Jamie or Sally directly. We will contact the families in January to see if progress has been made with the issues they raised.