

ADULTS AND HEALTH SELECT COMMITTEE

10th May 2024

Children and Young People's Emotional Wellbeing and Mental Health – Mindworks and the Neurodevelopmental Pathway.

Purpose of report:

1. The Adult and Health Select Committee have asked for evidence and information on the system wide response to support the needs of Children and Young People (CYP) who may have Autism (ASD) or Attention Deficit Hyperactivity Disorder (ADHD), including details of the Neurodevelopmental (ND) diagnostic pathway provided by Mindworks.
2. Mindworks is an alliance of emotional wellbeing and mental health providers that includes Surrey and Borders NHS Partnership (SABP) as the NHS Trust, Tavistock and Portman leading on system change (i-Thrive in Surrey model described in Appendix 1) and 13 Voluntary and Community Sector (VCS) partners coming together under Surrey Wellbeing Partnership (SWP), of which three VCS partners also provide specific support in the ND pathway. SABP and third sector partners provide support and assessment for ASD and ADHD as part of the ND Pathway for children over six years of age.
3. This report provides an overview of the status of provision and performance. It acknowledges that providers of support are challenged in their ability to provide a comprehensive response as are schools and families, and that change is required within the context of; increased needs and demand, pressure on staff (including those in schools) and families and diminished financial resources across health, local government, and schools.
4. The proposed cultural shift, described in the report, to a social model of support, requires action across the system and continued recognition that there remains considerable work still to be done in meeting the needs of CYP with Autism Spectrum Disorder (ASD) or ADHD. The work detailed within the ND Transformation Plan builds on that of the All-Age Autism Strategy, helping to provide a focus on specific areas for improvement through a needs-led ND pathway.

Introduction

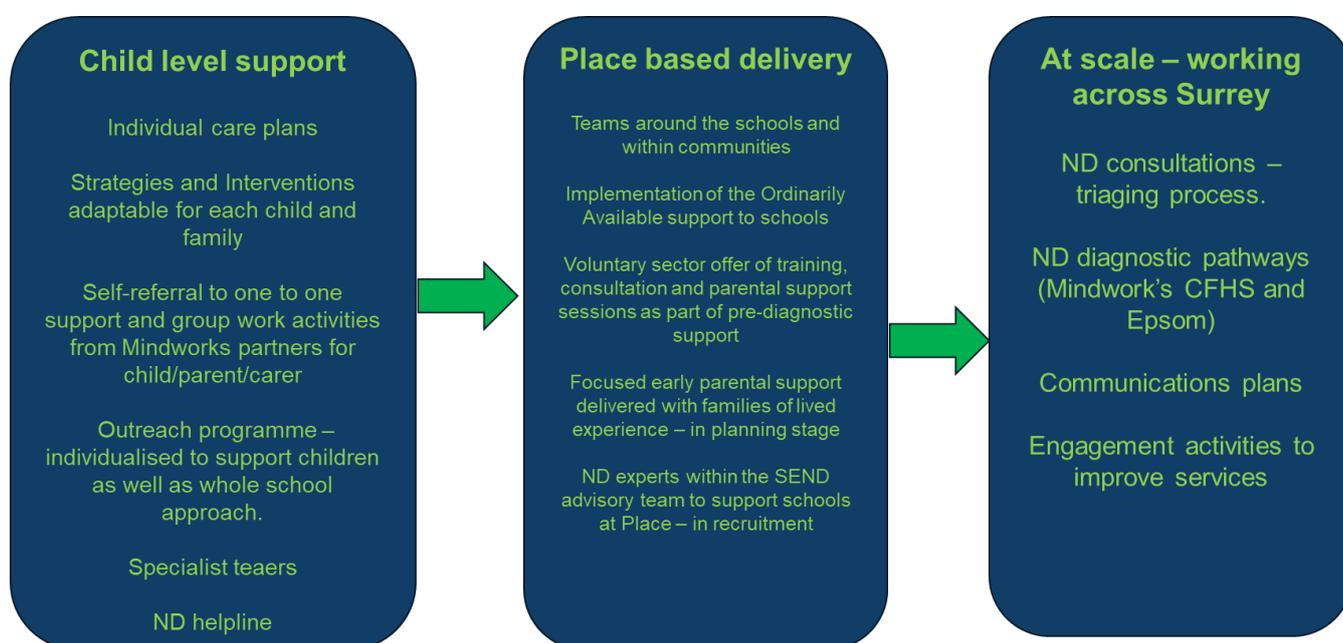
5. Autism (ASD) is a developmental disability caused by differences in the brain. People with ASD often have problems with social communication and interaction, and restricted or repetitive behaviours or interests. People with ASD may also have different ways of learning, moving, or paying attention.
6. ASD is a lifelong developmental condition that can affect many areas of a child or young person's life, and whilst diagnosis can be important for self-identity, there is no formal treatment. The most important form of help and support for Autistic CYP is having access to strategies and interventions that can help a child to manage and reduce some of the difficulties they may experience, alongside building on the strengths and talents that are specific to any one child or young person's autism. Providing support is not something that one organisation or agency can do alone. A child-centred, joined-up approach across education, health and social care is required, recognising that families may need to access support at different stages of the child's journey.
7. ADHD is a condition that affects people's behaviour. People with ADHD can seem restless, may have trouble concentrating and may act on impulse. CYP with ADHD, may have difficulty concentrating, hyperactivity and act impulsively. Some may present with difficulties with one or more of these issues and like Autism, ADHD requires a child and a family to implement strategies and interventions alongside their support network including school. Medication is also an important adjunct in the treatment and management of the condition for those young people who have moderate to severe ADHD.
8. Neurodevelopmental demand has increased both locally and nationally. Latest research and NICE Guidance suggest that the prevalence of ASD and ADHD in CYP is up to 2.6 % and 4.6 % respectively. If these figures were applied to Surrey, with 197,000 CYP between 5 and 17 years of age, there would be approximately 5,200 CYP with ASD and 9,000 with ADHD, although we also recognise that some CYP may have both. Either way it is significantly above the current 1% population investment for ND diagnostic services.
9. CYP and their families seek support in meeting their needs early, as well as in relation to assessment and diagnosis. More details of what parents and CYP tell us about their ND needs are provided later in the report in figure 5 and in appendix 2. ASD is the primary need within a third of EHCPs in Surrey and schools are responding to and seeking more support to help CYP. However, there is also a recognition, that CYP needs are changing, and we need to work together to support them within mainstream settings. An example to illustrate this is:

“the breadth and depth of neurodiversity within classroom is different today and we need to work together to create neurodivergent thriving communities” Local Primary School Head.

10. Schools continue to be measured by academic achievement and attendance, and would like to be able to respond differently, but face their own challenges in respect of resources and capacity. Public Sector finances are similarly constrained, and there is pressure to work within those that are available. Many sectors face significant workforce difficulties, and this further contributes to limited access to support and longer waiting times.

11. The result of this is that, despite a range of available support (figure 1), many CYP are waiting for significant periods of time to access ND diagnosis and support. Audits and feedback from our Surrey families confirm that over one third of the CYP referred for ND diagnosis may not have ND needs and may be seeking support which is considered only accessible after a diagnosis or looking for ‘a magic fix’ (quote from a parent).

12. Figure 1:



13. In December 23, the Integrated Commissioning Team identified that due to both demand and capacity, which is exacerbated by the requirement to reduce any overspend and return to the commissioned financial envelope, [Mindworks](#) was at a critical stage of maintaining delivery of the ND pathway. There was a need for immediate action to establish a recovery plan and so [Mindworks](#) was placed into business continuity. Business continuity illustrates, from the ICB’s perspective, the level of concern around the length of time CYP are waiting for support. The same concern was raised across the system as part of the recent Area SEND inspection.

14. The Inspection, in Surrey, complemented the work of the All-Age Autism Strategy but raised the importance of prioritising improvement in assessment and waiting times to support children with ND needs. The challenge is making these improvements and meeting increasing need and demand within currently available finances.

The Mindworks ND pathway, including performance and outcomes.

15. [Mindworks](#), SABP and third sector partners provide support and assessment for ASD and ADHD as part of the ND Pathway for children over six years of age. The current Mindworks pathway is described in appendix 3.
16. Other providers also deliver this service; for children under six years, for the whole of Surrey, this is Children and Family Health Surrey and children living in the boroughs of Mole Valley, Epsom and Ewell, Reigate and Banstead can be supported by Epsom Hospital.
17. Across Mindworks, Surrey's children and families are seeking support through the wide range of available routes and provision. Early intervention partners including SWP, Barnardo's and the National Autistic Society are seeing more demand which reflects that families are telling us they want to be supported sooner.
18. At present the performance arrangements are attached to referrals and activities, which does not provide an understanding of caseloads or numbers of individual CYP/Families supported. (Please note this is being changed in the refresh for year 4).
19. The total contract values in the Mindworks ND pathway are **3,968 referrals and 24,729 activities**. As of Feb 24, month 11 the performance against these targets were: (see appendix 5)
 - **SABP**: Referrals (Demand) is above contracted levels at **4119** referrals received Year To Date (YTD) variance **-150%** Activity: there are data quality issue resulting in separate manual reporting illustrated below in figure 2 and 3.
 - **Barnardo's** Referrals (Demand) is below contracted levels at **1,074** referrals received YTD variance **-2%** Activity is below target at **6,492**. YTD variance **-6%**
 - **National Autistic Society** Referrals (Demand) has exceeded contracted levels at **2,818** referrals received YTD variance **tb** Activity has exceeded the target at **12,639**. YTD variance **tb**. This includes non recurrent activity and improvements in reporting are therefore being made to be able to confirm variance
 - **Learning Space** Referrals (Demand) has exceeded contracted levels at **502** referrals received YTD variance **+60%** Activity is above target at **3,827**. YTD variance **+24%**
20. Due to data quality issues, SABP produce the separate reports to support our understanding while they are in business continuity. This enables us to track impact on referrals and caseloads from when the changes were implemented to the screening process.
21. Currently there are 7,670 CYP on the pathway, a reduction from 9,178 (September 2023), the reduction has largely been achieved due to the change and limited access to referral processes at that time. Changes to the screening process, detailed in appendix 3, have meant that those children who were already waiting to be screened have been reviewed more quickly. Figures 2 and 3 below illustrate this point. As anticipated, activity

has increased in the diagnostic assessment and for ADHD medication. We are awaiting confirmation from SABP of the projected impact from the additional investment outlined in Table 1 which is anticipated to be from the beginning May '24.

Figure 2: Mindworks CYP ND pathway reporting, April 2024

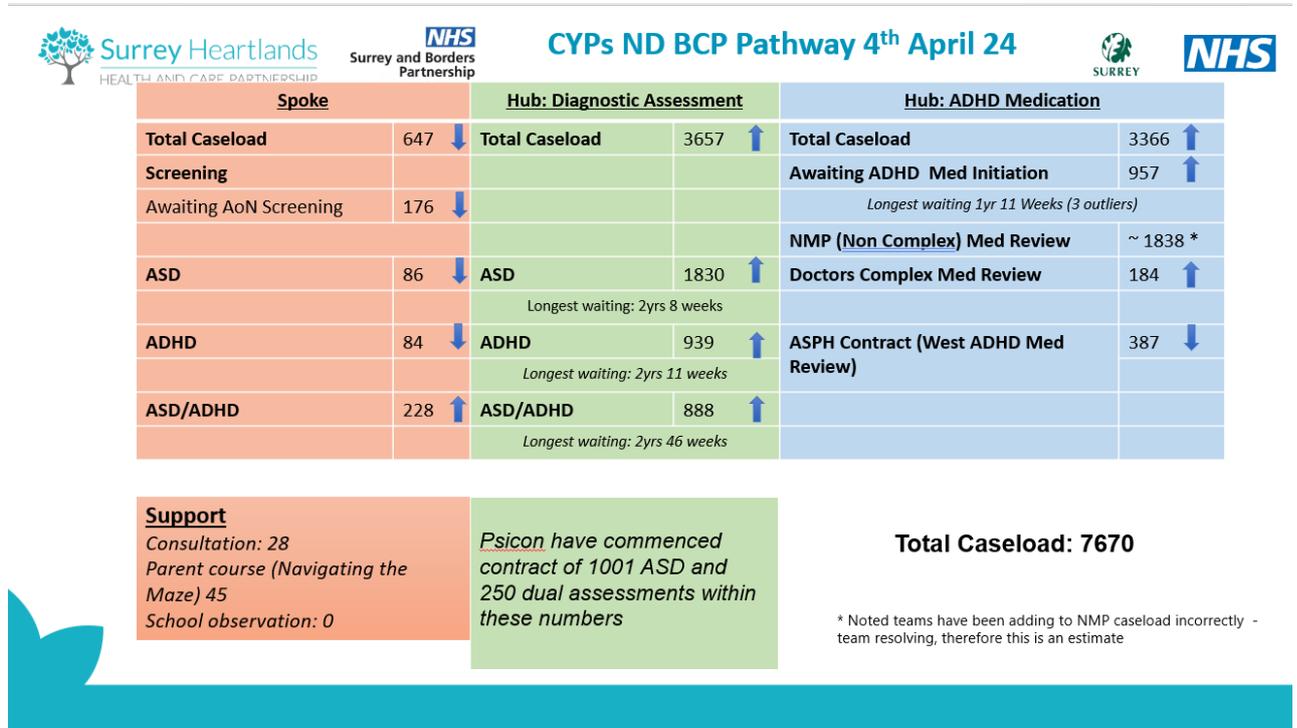
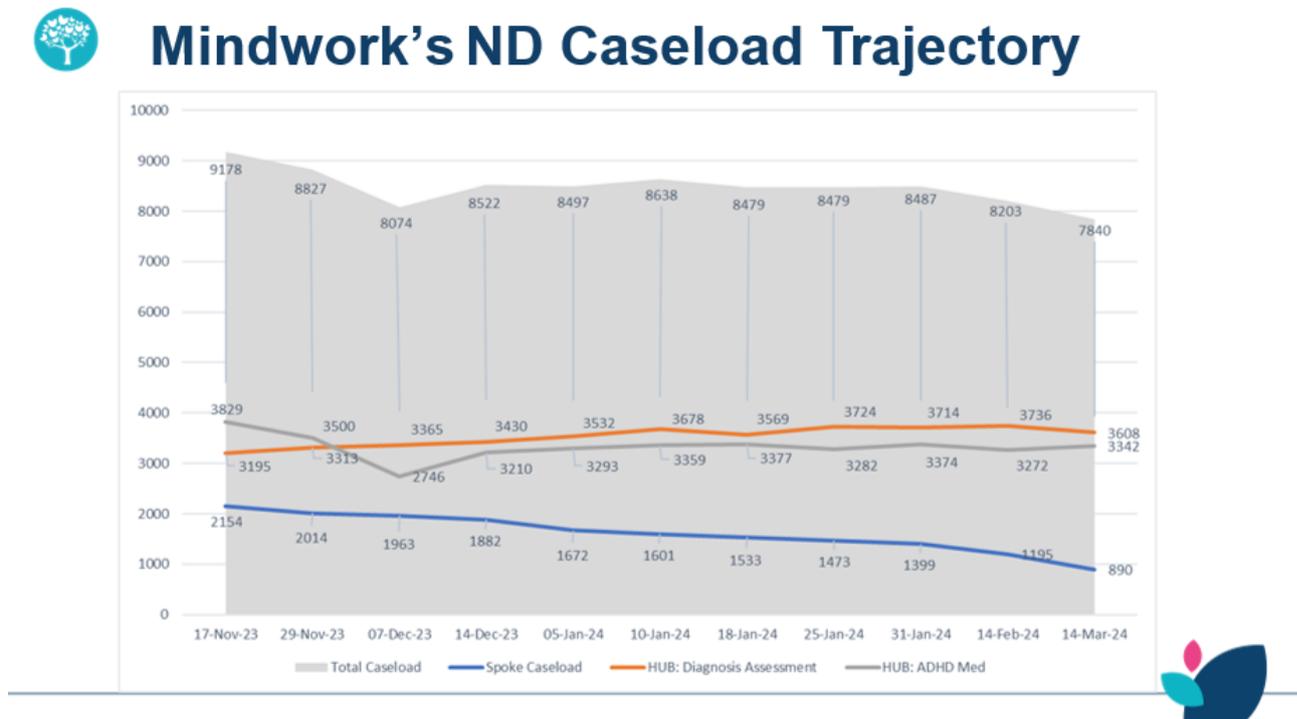


Figure 3: Mindworks ND caseload, March 2024



* There remains data quality issues related to the Mindworks BI dashboard collecting all relevant data for partners and so the SABP performance data above is from the weekly escalation calls.

22. Outcomes Summary: please see appendix 6 for full report.

23. Mindworks and commissioning colleagues attended the Adult and Health Select Committee in February 2023. At that time, the process for the recording and reporting of outcomes was being developed. Mindworks have made progress in this area and have been able to report outcomes across several services, since August 2023, through a strategic outcome framework along with coproduced experience questionnaires.

24. Goal Based Outcomes (GBO) are agreed with the CYP or groups at the outset of their support and reviewed again at the end which enables distance travelled to be measured. Shared decision making in working towards these goals ensures the voice of the CYP is at the heart of the work. This work is key to understanding the effectiveness of the support provided and the experience of CYP/Groups involved.

25. Targets for outcomes are:

- a. 50% of **discharged referrals** have at least one paired outcome.
- b. Of the 50% with at least one paired outcome, 70% of those show an **improvement** in **all** their goals compared to target.

26. Key highlights from Mindworks Q3 Outcomes report are:

- All partners evidence the use of goal-based outcomes (GBO) which demonstrates that CYP are central to decision making about their own care and treatment / interventions, a central principle of working in a Thrive approach and **all** partners are achieving above target for their goal improvement.
- Barnardos were able to evidence GBOs for 60.5% (192/317) of CYP discharged from the support provided in Q3. 89% of these CYP showed an improvement in all their goals.
- National Autistic Society were able to evidence GBO for 100% (23) of CYP discharged from the support provided in Q3. 95.7 % of these CYP showed an improvement in all their goals.
- Learning Space were able to evidence GBO for 100% (52) of CYP discharged from the support provided in Q3. 94% of these CYP showed an improvement in all their goals.
- SABP were able to evidence GBO for 16% (176/1100) of CYP discharged from the support provided in Q3. 84% of these CYP showed an improvement in all their goals. It needs to be noted that a digital solution is now in place for SABP to report outcomes starting Q4, and it is anticipated this will improve the % reporting against discharge.

27. Key highlights from Mindworks Service User Experience Questionnaires are:

- 4.59 out of 5 rated overall experience of support as positive.
- 4.55 out of 5 reported they would recommend the service to a friend.
- SABP's 46 responses to Your View Matters showed that 87% rated the service as good or very good.

28. It is recognised that there is further development to be done in capturing performance, GBOs and Experience Questionnaires across all the Mindworks services. Whilst the refresh of the information, activities and performance (IAPs) for year 4 will improve clarity on reporting, there remains a challenge to achieve the full reporting picture (locally and nationally) with the digital transformation budget being reduced by £1m. This is a risk identified and at present, there is no timeline for mitigation.

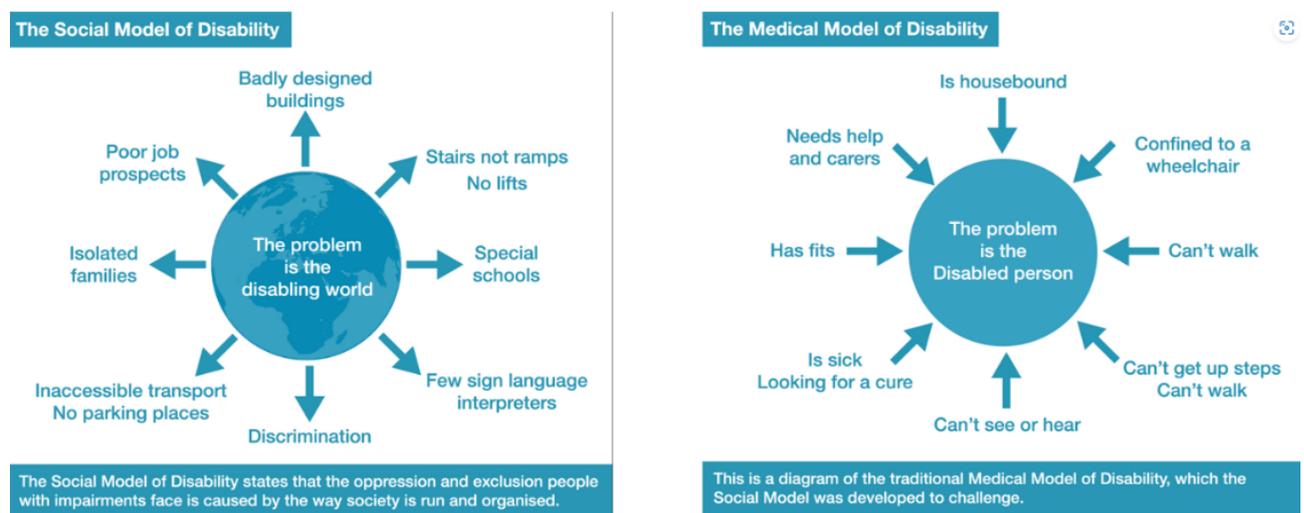
Children and Young People’s Neurodevelopmental Transformational Plan.

29. The scale of cultural change that is required to support the needs of CYP with ND is significant and should not be underestimated.

30. In response to what we are hearing, Surrey’s Inclusion and Additional Needs Partnership Strategy, is ensuring that partners adopt and embed the social model of disability (figure 4), underpinned by strength-based practice, and informed by CYP/ family’s needs. This is our preferred way to support neurodiverse CYP who want to feel welcome, safe, happy, and able to express themselves as they choose in the context in which they live.

Figure 4:

Social Model V Medical Model



31. Schools, families and CYP are a core part of the improvement work. They are part of, and integral to a range of established reference groups, forums, workshops, and surveys. Through these collaborative approaches with CYP, families and schools, we

have brought together key messages and themes (figure 5) which have been central to the development of the ND Transformational Plan (figure 6). This forms the detail behind the action in priority 3.3 of the SEND Inspection improvement plan ([Local Offer](#)) to 'ensure a refined neurodevelopmental pathway encompassing early intervention, support, assessment, and post-diagnosis'.

Figure 5: Summary of messages from CYP and Schools

Children and families tell us	Schools tell us
<ul style="list-style-type: none"> • Rebuild trust by prioritising relationships with families; schools must consider parents' views. • Involve the voices of carers, families, and young people in decision-making as this offers valuable insight. • Set up swift support networks for parents, encouraging open dialogue on sensitive topics. Connecting parents with similar experiences; ensure parent-carer forums actively support knowledge-sharing. • Tackle parents' needs, offer emotional support, and improve collaboration amid a lack of specialised provisions. • Despite the All-Age Autism Strategy, systemic issues endure, leaving parents unheard in critical decisions – more capacity required. • Waiting times reduced. • CYP involved in decision making. 	<ul style="list-style-type: none"> • Schools feel overstretched, under resourced and struggle to provide adequate support despite high pressure from educational bodies to do so. • Schools are reporting concerns in dealing with distressed behaviour. • Some school leaders and SENCOs may lack the training/understanding of neurodiversity and its implications. • The crucial role of school leadership in embracing ND is often overlooked, a culture shift is needed. • A needs-led approach is required but barriers persist in using available resources and Ordinarily Available Provision (OAP), hindering basic reasonable adjustments for neurodiverse students. • Parental support requires personal interaction as parents often receive only website lists following diagnosis. • Primary schools have led a ND survey to identify approaches to work together to support need.

32. Immediate, medium- and longer-term changes are being put in place. Surrey Heartlands ICB has recognised that there are more people on waiting lists who are waiting longer, and this is not acceptable from a quality and safeguarding perspective. The ICB want to limit this from happening as well as ensure focus is maintained on earlier support. A non-recurrent investment (£0.5m) was made, in December 2023, to support the pathway and address some of the current waiting times. SABP have also overspent in this area to increase assessment capacity, focusing initially on those who have been waiting longest and have greater clinical needs. At the same time, underspends in other pathways, have been redirected and a national funding bid have allowed for further investment to be made into this priority area.

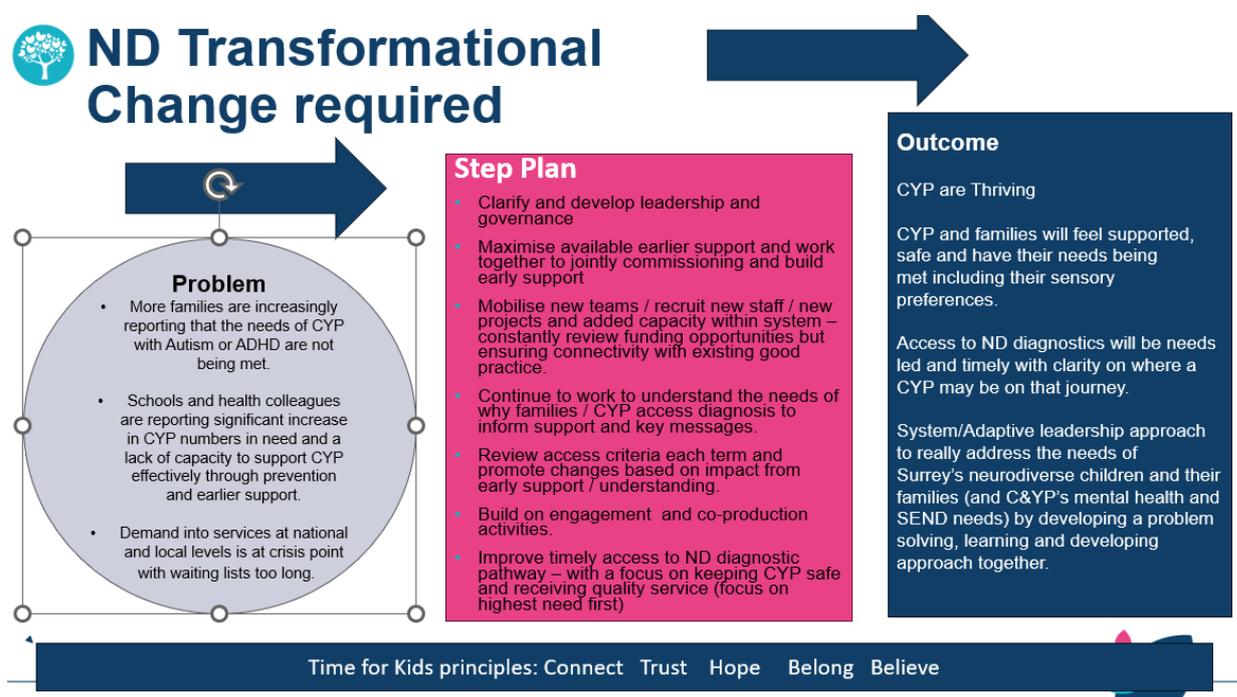
33. Table 1 provides a summary of how the one-off investment has been allocated. Investment areas support short- and longer-term improvement and were prioritised in accordance with risk and demand, as part of the ICB business continuity process.

Table 1: Summary of investments in response to Mindworks business continuity (items 1-3) and wider funding (items 5-6).

	Investment area:	2023/2024
1	Early intervention total investment: 4 x ND Advisors within Learners Single Point of Access (LSPA) Team	£117,000
2	Screening and Access to ND Pathway: recruitment of additional 3 assistant psychologist to support diagnostic assessments	£27,000
4	Diagnostic Pathway: ADHD / ASC / dual. Expand Pscion contract and increase capacity / expertise to move from Autism and ADHD separate hub to a combined diagnostic hub.	£475,000
5	The Mental Health Support Teams (MHST) have invested over an 18 month period extra parental support sessions co-delivered with people with lived experience and named lead in each district and borough	£465,000
6	Implementing Partnership for Inclusion of Neurodiversity in Schools (PINS) for primary schools. (£1.2m additional investment Q4 23/24) PINS local page details in here	£1.2M 24/25

34. Additionally, the ND Transformation Plan is provided in appendix 4, and this describes the wide range of improvement, activities and intended outcomes that have been put in place to drive change and support implementation of a social model of support. Figure 6 below provides a summary of the change required.

Figure 6: Summary of the ND Transformation Change required.



35. Improvement work is not solely relying on additional investment. With clear understanding that children, families and schools require more support, Mindworks have made the following changes to the pathway.

- Joint working with schools is growing and the partnership including Mindworks, education and additional needs colleagues will develop this further. ND experts within the screening and triage team will work alongside SEND professionals to understand the needs of children and ensure onward support, from third sector partners within Mindworks, as well as assessment where required. ND practitioners now work closely with SENCOs via the Consultation approach (described in appendix 3). This includes the ability to use data from schools and referrals to pro-actively direct support, rather than solely schools reaching out for support.
- A series of engagement activities with families and CYP have started, with the aim of consulting on changes and communicating more clearly.
- Parts of the pathway are being digitalised to support quicker screening and diagnostics.
- Further expansion of the VCS offer is planned through the Mental Health Investment Fund allocation (£1.2m over 2 years) which will enable an expansion of SWP provision of early intervention coordinators, who will now expand and provide direct support to all primary schools. This will enable all primary schools to have an identified named lead and access a package of early intervention support that will see improved goal-based outcomes for Emotional, Mental Health and Wellbeing for

both children and parents. These co-ordinators are trained to support CYP with ND enabling equitable access to all in need of early support.

- Mental Health Support Team investment has increased the provision of direct support to families of CYP with autism or ADHD with named leads in each district and borough, providing parent support co-delivered with people with lived experience. This direct provision is via Surrey Wellbeing Partnership.
- All partners across Surrey Wellbeing Partnership have received training to support CYP / families with neurodiversity, to enable access for all to the packages of early support.
- Psicon have been commissioned by SABP to deliver additional autism and ADHD assessments. There are expected to be over 1,400 referrals, currently in the backlog, addressed via this route.

36. An immediate, but short term, response to the challenges within the Mindworks ND pathway has led to more capacity for assessments for those children already waiting. It has also brought together colleagues and partners from different parts of the system to focus on what is required to support the needs of children with autism or ADHD, irrespective of a diagnosis assessment. The preferred social model of support will take time to achieve at a scale sufficient for families and children to feel a difference, however, this longer-term approach is required to ensure CYP can reach their full potential.

Risks and continued challenges:

37. Much focus is placed on the assessment process for Autism and ADHD. However, an area that has grown in concern due to the clinical needs of the children, is where they are waiting for initiation or review of medication for ADHD. This part of the pathway has become more challenged over the last 3-6 months, initially due to availability of medication, and more recently due to workforce capacity.
38. Mindworks are commissioned to support the initiation of ADHD medication for ~600 CYP. As of March 2024, there are currently ~3,342 YP on the ADHD Medication pathway, this includes the ~939 YP waiting for medication initiation, some of whom will be waiting over a year to be seen. Children on the pathway and with medication in place should be reviewed every 6 – 12 months, depending on their needs. Currently, some children are not being reviewed within these timelines and this can impact on their ability to thrive. Key to support this is the development and implementation of a local commissioned service with primary care to discharge CYP on stable medication to primary care for reviews.
39. The unprecedented surge in demand for ADHD diagnosis has happened at such a scale that it stands out as a serious problem, even amid the wider challenges affecting health services. NHS England is **establishing a taskforce** on ADHD to improve understanding of this condition. A wider debate about the role of the NHS in the assessment, diagnosis and treatment of neurodivergent conditions is needed. In a health and care system

where resources are so constrained, a broader response is likely to be required, working with other sectors including education.

40. Detail of the risks, within the health system, associated with the waiting times for support and assessment on the ND pathway is included in appendix 7. They broadly describe the risk and impact of the lengthy waits experienced by many children and young people.
41. The ND improvement plan will further refine these risks to ensure they represent the system challenges and especially those faced by CYP and families. It will provide mitigations, where possible, and ensure escalation when required.

Conclusion

42. Programmes of work that include education, health and local authority partners have been identified to start to change the response across Surrey. A clear communication and engagement plan is being developed to ensure that families and CYP are kept informed of how their needs can be met – with or without the requirement of an ND diagnosis. The plan is in final stages of sign off which is anticipated to be by the end April 2024.
43. Demand and financial recovery within the Mindworks Partnership will be balanced alongside ensuring provision of high quality and safe services. It is recognised that even after obtaining, short-term, system financial support, improvements will not be felt by all of the workforce nor all CYP and families.
44. There are significant pressures on families and CYP, directly attached to supporting the needs of CYP with ASD or ADHD. Achieving improvements in supporting these needs when finance is challenging across the public sector, means we must do things differently. A cultural shift, to a social model of support, is required to respond to those needs earlier, irrespective of whether a diagnosis is sought. The ND transformation plan starts to articulate the steps being taken to implement this model and approach.

Recommendations:

45. In recognition of the changing needs of the population, we recommend the Committee continues to acknowledge and appreciate the impact that the financial, workforce and demand challenges are having on the ability of health, education, and social care to meet the needs of neurodiverse CYP. In turn, this has an impact on CYP and their families and we ask that the committee advocates for developing a social model of support across Surrey.

Next steps:

46. Reporting on the ND improvement plan will take place through the Additional Needs Partnership Board. It is part of the SEND Inspection Improvement Plan and reporting to

the board will support maintaining the partnership approach to change and provide a platform to seek support.

47. Engagement with schools, families and CYP will continue through established networks and groups, providing a place for continual feedback.
48. Oversight on the quality of provision and any associated risks will be monitored through monthly provider oversight meetings.
49. A review of specific services that support CYP with a Learning Disability and or Autism is currently underway and will further shine a light on their needs at time of crisis.
50. The Committee may be interested in the impact on specific groups of CYP, for example, those who are looked after, jointly scoping a piece of work to understand this further could be undertaken.

Report contact

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Sources/background papers

[List of all documents used in compiling the report, for example previous reports/minutes, letters, legislation, etc.]

List of appendices

1. i-THRIVE in Surrey
2. User Engagement Summary
- 2a. School Reference Groups and Messages
3. Current delivery and lessons learned
4. ND Transformation Plan
5. Performance data
6. Outcome report
7. ND pathway system risks