# Action Card

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| Card number | 009 |
| Project | Mindworks Surrey and ND Pathway |
| As a | Group of parent carers who find the restricted access to and wait times for the assessment and diagnosis pathways for Autism and ADHD for their child or young person unacceptable, because these are lifelong disabilities with extremely poor outcomes.  **Key Concerns:**  **1. The move away from a medicalised model to a needs-led, social model around early help, should not negate the duty upon the Integrated Care Board and Surrey County Council, as determined in the NHS England guidance for a national framework, for timely access to a diagnostic pathway**  [NHS England » A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards](https://www.england.nhs.uk/long-read/a-national-framework-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/)  This says: “it is important that ICBs do not restrict or withhold access to an autism diagnosis, for example, because locally a decision has been taken by health to conduct only a needs-based assessment. Barriers to a diagnosis increase a person’s risk for poor outcomes in life.”  **2.** **That the current consultation process through schools is restricting access to the ND Pathway for diagnosis and assessment for children and young people (CYP) who mask.**  This highlights that CYP are not being looked at holistically as the needs and behaviours are primarily being examined within the school setting, or with self-referrals in the home environment.  Parent carers need to be recognised and acknowledged as the experts, with their overarching views central to decisions around CYP.  **3. Wait times for CYP currently on the ND Pathway for, or awaiting access to, an assessment and diagnosis for Autism and ADHD.**  The absence of a (digital) integrated tracking system leads to inconsistency with check-ins for CYPF, and access to timely signposting to resources and support services whilst waiting. CYPF consistently report that they don’t know where they are ‘in the system’.  **4**. **The number of exclusions in schools are rising. Is there a link and correlation between those CYP on the waiting list or who need to be on an ND diagnostic Pathway?**  The Percentage of pupils who experienced permanent exclusion or suspension during primary school who have SEND is **97%**  ([Too Young to Leave Behind - full branded report\_Final (chanceuk.com)](https://www.chanceuk.com/wp-content/uploads/2024/04/Too-Young-to-Leave-Behind-full-branded-report_Final.pdf)).  **5.** T**he belief and concern are that the current restricted access to the ND Pathway for diagnosis is leading to increased suicide ideation, suicide attempts and suicide.**  **99%** of school leaders say the funding they receive for pupils with SEND is insufficient (NAHT).  A “Key Learning” on the briefing paper for the Adults and Health Select Committee Public meeting on 10 May is that schools are “on their knees”.  NAS: Studies have shown high rates of suicidal thoughts (10.9% – 66%), and suicidal behaviours (11% - 30%) in autistic adults and children  [Suicidality in autism: risk and prevention](https://www.autism.org.uk/advice-and-guidance/professional-practice/suicidality). RSPCYCH state this differently: [Suicide and Autism, a National Crisis. (rcpsych.ac.uk)](https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/suicide-prevention/workshops-(wave-4)/wave-4-workshop-2/suicide-and-autism---slides.pdf?sfvrsn=bf3e0113_2) ‘Autistic children are 28 x more likely to think about or try suicide’.  **6. The lack of a formal joint ICB and Surrey communication and engagement policy, to provide timely, integrated and consistent updates and engagement opportunities for parent carers, CYP and schools alike.**  Parent carers do not feel that they are kept up to date and that communication is irregular, inconsistent and lacks transparency.  There is no formal mechanism to effectively monitor, review and deliver integrated communication and engagement opportunities that adopts consistent and accessible language.  **7. The increase in families seeking access to ADHD and/or Autism diagnoses via Right to Choose or privately.**  The current wait times and restricted access for assessment and diagnosis to the ND Pathway, is resulting in families alternatively seeking assessment through Right to Choose via their GP’s, or paying privately if able to do so.  The impact of this is twofold:   * Further increased financial pressure upon families, with creation of wealth division between those families able to fund private assessments and those who cannot. * Lack of clear guidance from ICB on criteria for Right to Choose and private assessments, leading to confusion around outcomes and measures from assessments, eg, families reporting schools unclear on validity of reports outside of Mindworks AAT pathway |
| We want | 1. 1. A joint statement from the ICB and Surrey in line with NHS England guidance, confirming its commitment to timely access to an assessment for ADHD and/or Autism for those children or young people who require it.   For this to include evidence of statutory compliance in light of the recent Bristol legal challenge around restricted Autism assessments.  [Decision reversed to restrict autism assessments in Bristol - BBC News](https://www.bbc.co.uk/news/uk-england-wiltshire-65430686)   1. Clear and specific guidance on children and young people who mask, and access arrangements to the pathway for these CYP who present differently at school than they do at home. 2. Clear and specific guidance in accessing the diagnostic pathway, for those children and young people unable to attend school. Whether on school roll or off-roll due to EBSNA or Alternative Provision. 3. In the development of a new pathway, evidence of plans and measures to ensure comprehensive and accessible (digital) tracking facilities for families and professionals for CYP on wait lists. 4. Provision of data to identify how many CYP that have been excluded are currently on a wait list for the ND Pathway or are awaiting assessment to be added. 5. Provision of data to identify the impact of the current restricted access to the ND diagnostic pathway, has had on CYP experiencing suicide ideation, suicide attempts and suicide. 6. Provision of a joint ICB and Surrey policy for integrated communications and parent carer engagement, in the development of Mindworks services and the ND Pathway.   This is in line with measures determined within the SCC Local Area Improvement Plan, specifically but not limited to Improvement 2: *Relational Working and Communication*   1. Clear guidance for families seeking an ADHD and/or Autism assessment and diagnosis for their child or young person through Right to Choose, or for private assessments, with consistent and integrated guidance, relevant to CYPF, GP’s and schools. |
| So that | Children and young people have their neurodevelopmental and mental health needs assessed, identified and diagnosed at the earliest opportunity, so that they can thrive and that their statutory rights remain unaffected.  There are equal opportunities for all children and young people needing to access the pathway for ND assessment and diagnosis, and that they are not disadvantaged by their social or economic status in doing so. |
| Allocated to | Kerry Clarke, CYP Head of EMHW Commissioning, NHS Surrey Heartlands  Lisa Nash, Integrated Commissioning Officer, Surrey County Council |
| Accepted by |  |
| Outcome measure | * A joint statement from the ICB and Surrey CC, to be publicly available on the Local Offer and Mindworks Surrey website, acknowledging the impact and severity of the problem and identifying improvement measures. * Freely available data for wait times, to allow for analysis through improved tracking function. * CYP who mask to have equal opportunities. * CYP with EBSNA to have equal opportunities. * A reduction in the number of CYP with ND or suspected ND who are suspended or permanently excluded. * Meaningful and consistent updates for parent carers, that align with communications with schools and practitioners. * Regular engagement meetings between joint senior policy makers and parent carers will be held, to inform and shape policies and services. * A reduction in the number of CYP experiencing suicide ideation, suicide attempts and suicide * Data for referrals via Right to Choose pathway for assessment. |
| Date Received | 02/08/2024 |
| Dates of updates | 19/11/2024 |
| Date Closed |  |
| Publishable response |  |