



Position statement on the neurodevelopmental pathway in Sussex May 2024

Summary

Transformation of the neurodevelopmental pathway (NDP) has been the subject of numerous reviews, deep dives, workstreams, meetings, and action groups. Despite two successive review processes having been concluded by NHS Sussex in the last two to three years, at great cost to the system, there remains no clarity around a way forward to reduce the alarming situation families face in accessing support for their child or young person awaiting assessment, diagnosis, and support with a neurodevelopmental condition. The overall goal of developing a simplified, combined, and efficient pathway for ASC, ADHD, and co-occurring conditions feels more distant than ever which compels us to write this position statement, to set out our shared concerns and the strongest of pleas for urgent action.

1. Access to support for neurodivergent children and young people urgently needs to improve.
2. Communication, information, and signposting must strengthen – across all areas of the pathway and between services, parents, and schools.
3. Capacity needs to be allocated across the system to turn recommendations – as identified in successive transformation workstreams – into action to achieve a single, joined up ND pathway.

Some of our key concerns

Previous consultations and reports by the parent carer forums (PCFs) and across the NDP workstreams have detailed families' experiences and concerns, so we don't attempt to repeat all these here. Instead, our focus is on some key headline concerns, which are:

1. **Access to support for ND children and young people needs to urgently improve**- particularly when there is no diagnosis, around mental health, in early years, post-16, and when a child or young person isn't attending school/college.
 - a. Some leaders in education, health, and care insist that support is available in school and needs can be met without diagnosis, as per the legal framework, whereas others dispute this, aligning with parent carer feedback that a lack of assessment and diagnosis persists as a major barrier to accessing support. These circular conversations are frustrating and persist in NDP workstream meetings. Meanwhile commissioning of some services, eg Keyworker, continue to link eligibility thresholds to diagnosis.
 - b. Questioning the need, and reducing demand, for assessment and diagnosis has become too much an emphasis in the transformation agenda – so that the focus is resource and service driven, rather than on the needs of children and young people. This can also overlook the importance many young people (and adults) attach to receiving a diagnosis, which they say is integral to their wellbeing, as well as more practical issues such as securing adjustments in the workplace.
 - c. Differences in eligibility criteria and the commissioning/provider landscape across localities maintains a sense of confusion, inequity of provision across Sussex, and presents real or perceived barriers to families accessing support. The complexity of change management at this level is not easy but needs tackling. We feel leadership has been affected by NDP personnel changing frequently and a succession of interim postholders, which persists today.
 - d. NDP transformation agendas have not focused at all on the acute end of the pathway. This means when the SEND (special educational needs and/or disabilities) communities across Sussex ask their parent carer forums and Amaze what is happening to address the systemic failures in the system identified by inquests, such as that of Jessie Eastland-Seares, we have no information we can share and are not reassured that much-needed service development is happening.

2. **Communication, information, and signposting must strengthen** – across all areas of the pathway and between services, parents, and schools, resulting in better understanding of the system and where families sit in it. With transformation stalled and the pace of change slow, there needs to be immediate improvement in how the current system is working for families.
 - a. Consistent, honest, and clear communication is required from **all** providers in an agreed standardised format (one letter template) with agreed timeframes so that parent carers are updated as to where they are on the waiting list. Keeping in touch letters/texts (offered by some services) should help to reduce anxiety and the need for families to call child development centres (CDCs)/Child and Adolescent Mental Health Services (CAMHS) for updates.
 - b. Clearer explanations are needed on the outsourcing of assessments to reduce waiting times.
 - c. Communication around private diagnosis remains confused: who accepts/doesn't accept a private diagnosis-and what support will/won't it give access to, persist as frequently asked questions.
 - d. There needs to be greater consistency in how diagnosis is communicated: how, what, and when. Use of flowcharts giving clear visual explanations regarding the NDP including referral criteria and waiting list management would help a lot.
 - e. Greater clarity and transparency are needed at a system level around waiting times, which remain veiled in secrecy or confusion, or 'going through validation processes'.
 - f. It is positive that the NDP Family Support Service has been commissioned to provide navigation, family training, and peer support to parent carers. Navigators have developed information resources to support their work, but parents themselves need access to centralised, online information, on all aspects of the NDP, rather than this being scattered across different provider websites.
 - g. Services need to listen to parent carers, ensuring they feel heard and respected, and their experiences and expertise valued and included. It is unacceptable that parent blaming persists and that this culture hasn't yet fully shifted – more training for staff in parent carer awareness would help. There is still a need for better understanding from practitioners within CDCs and CAMHS on the presentations of neurodiversity. This gap heightens anxiety for parent carers.
 - h. Stories need only be told once, not countless times as remains the case with current pathways – undoubtedly adding to long waiting times to access services.
 - i. There have been various attempts at communication plans about the transformation programmes, time spent commenting on draft copy/stakeholder maps/priorities etc, but time moves on, and the community waits for news of real change. The PCFs and Amaze cannot communicate 'change management speak' as this is meaningless to families.

3. Capacity needs to be allocated across the system to turn recommendations – as identified in successive transformation workstreams – into action to **achieve a single, joined up ND pathway**.
 - a. Learning from the Portsmouth profiling tool needs to be properly worked through, to decide what is appropriate for Sussex, with families, clinicians, and education providers co-producing our approach.
 - b. There is a danger of new projects, driven by funding, further complicating an already crowded landscape, e.g. PINS and Autism in Schools. This needs to be carefully managed to avoid confusion on the ground and chaos in the system.
 - c. The plethora of boards/actions groups/meetings needs reviewing and streamlining, with clarity of where decision making responsibility sits. Similarly, a range of strategies exist, at place, across Sussex, and for different conditions. This can cause confusion and misunderstanding e.g. placed-based Autism strategies can be mistaken for offering solutions for other ND conditions when they do not cover this.
 - d. Services, systems, and processes vary across the three areas of Sussex, and we need both to be mindful of this when making plans and ensure it doesn't become a barrier to progress.
 - e. There is a lack of understanding of the PCFs roles and inconsistency in co-production.
 - f. The ongoing ADHD medication shortage highlights the gap in joint working between health and education. Parent carers feel that the response and information from health and education is lacking.