



Position Statement on the neurodevelopmental pathway in Sussex – a summary version

May 2024

We have written a position statement to highlight our concerns and ask for urgent action. We sent the statement to directors at NHS Sussex on 3rd May 2024. This is a summary version for families. To read the full position statement, go to [NDP position statement full version](#).

NHS Sussex has held lots of meetings and reviews over the last two to three years but there is still no clear plan to help families who are waiting for support.

Families still struggle to get help for children and young people with neurodevelopmental conditions such as autism and ADHD.

The aim is to have a clear and simple pathway for support and/or assessment and diagnosis. It feels like things are moving backwards rather than forwards.

Key concerns

Access to Support

- It's very hard to get help. Some people find it even harder to get support without a diagnosis, when there are mental health concerns, in early years (before school age), or after turning 16.
- Some local services are only available to children or young people with a diagnosis, such as the Autism or Learning Difficulties and Mental Health Keyworker service.
- It is not right to focus more on saving money and resources than on children and young people's needs. It feels like the work is being driven towards reducing the number of people asking for assessments and diagnosis.
- However, a diagnosis can be very valuable to help people understand themselves, as well as helping other people to understand them, such as at school or getting support at work.

- Rules for getting support vary between areas, which can be confusing for families and makes it hard to get support.
- There is no information about what is being done to fix failings in the system which have been identified by investigations, such as the inquest about Jessie Eastland-Seares. We don't feel confident that this important work is happening.

Communication and Information

- Families need better updates on how long they will be on a waiting list.
- It is confusing trying to understand if a private diagnosis will be accepted, and what support it might lead to.
- Information for families about neurodevelopmental conditions and local services should be in one place, online, and easy to find.
- Services need to listen to and understand parent carers' experiences better.

Capacity

- Recommendations to improve the system need to be put into action.
- New projects might make things more confusing. Good communication is needed so that families and services know who is doing what.
- There are too many groups and meetings. It may not be the best use of time, and it is not clear who can make decisions, which is confusing.
- Services differ between areas, making planning difficult.
- Services don't fully understand the roles of parent carer forums, so families are not always equally involved in the way they should be.

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