

healthwatch

Wandsworth

Experiences of the Emerging Needs Pathway

(The autism diagnostic pathway for 0-8 year olds in Wandsworth)



Report summary

'I start accepting that I'm not the only one who struggles, it's hundreds of parents just in Wandsworth who struggle' –

Parent of a child on the Emerging Needs Pathway

Background

In 2024, Healthwatch Wandsworth gathered public feedback which identified the mental health experiences of children and young people (CYP) with autistic spectrum disorder/condition (ASD/C) and/or attention deficit hyperactivity disorder (ADHD), as a relevant health and social care priority.

In the summer of 2024, we heard of the NHS South West London Integrated Care Board's (NHS SWL ICB) plan to redesign the Emerging Needs Pathway (ENP – the autism diagnostic pathway for 0-8 year olds in Wandsworth). As a result, we decided to focus our project on the experiences of parents/carers with 0-8 year old children on the current Emerging Needs Pathway in Wandsworth so that their experiences could shape how the new redesigned pathway, which will be known as the Social Communication Difficulties Pathway (SCD) and run by St George's Hospital NHS Foundation Trust (SGH), develops and ensure that it works for local people.

Our Findings

As part of our project, we spoke to a range of individuals and organisations. These included:

- Parents/carers of children with Special Educational Needs and Disability (SEND)
- Local educational professionals
- Local and national voluntary organisations
- Local statutory organisations
- The NHS South West London Integrated Care Board

What we heard from parents/carers and educational professionals

The surveys we conducted with parents and carers and educational professionals highlighted themes for those going through the Emerging Needs Pathway (the details of these can be found in the full report):

- The process of getting a diagnosis
- The mental health impact on the child
- The mental health impact on parents/carers
- Availability of support

What we heard from organisations

From speaking with voluntary and statutory organisations several important topics were highlighted in relation to the Emerging Needs Pathway (the details of these can be found in the full report):

- Issues with the current pathway and the goals of the redesign
- Health inequalities & stigma around autism
- The importance of early intervention
- The role of voluntary organisations
- Support available while waiting for a diagnosis & an Education, Health and Care Plan (EHCP)
- Support after formal diagnosis

Our Recommendations

Healthwatch Wandsworth has put forward **eight key recommendations** for improving the experience of parents/carers and their children on the new redesigned Social Communication Difficulties Pathway. The full justification for these recommendations and their potential impact can be found in the full report.

1. Improved Communication

- We would suggest there is a strong need for better communication with parents and carers from NHS SWL ICB & the local authority. Parents/carers expressed feelings of being left in the dark, with many suggesting that regular updates and clearer communication about waiting times and processes

would reduce their anxiety and confusion. This includes providing updates when there is no progress and signposting to supports available while waiting.

2. Interdepartmental Collaboration

- We would call for different aspects of clinical care in NHS SWL ICB such as paediatric care, occupational therapy, speech and language therapy, to find more ways to collaborate and work closely alongside educational professionals and relevant voluntary organisations.

3. Multi-Disciplinary Assessments

- We would call for the NHS to consider the long-term benefits of moving towards a more holistic and streamlined approach in assessing neurodevelopmental conditions.

4. Clearer Processes and Guidelines

- We would recommend that a clear outline of the process of how to access the redesigned Social Communication Difficulties Pathway is made public by NHS SWL ICB and widely distributed to relevant parties.
- We would also suggest that a central directory is created by NHW SWL ICB & the local authority and is actively updated detailing all the relevant supports available for autism in Wandsworth and the requirements for accessing them. We are aware that this exists in some capacity through the Wandsworth Family Information Service, but a specialised autism related directory would be beneficial, and it is important that it is clear what the access requirements are, and services that can be accessed without a diagnosis need to be clear.

5. Early Intervention

- We would recommend that all parents/carers are informed by NHS SWL ICB & the local authority of the possibility to refer their child to the Social Communication Difficulties Pathway following atypical development and that the pathway provides the opportunity for developmental screening and regular check-ups to monitor the child's potential emerging needs.

6. Training and Education

- We would recommend that there is an emphasis placed by NHS SWL ICB & the local authority on providing a standard level of training and education to all relevant healthcare, social care and educational professionals to further their understanding of neurodevelopmental conditions and who they should signpost parents/carers to for further support.

7. Holistic Support During Waiting Periods

- We would suggest that if long waiting times are acknowledged as the norm for the foreseeable future in Wandsworth, due to the complexity of the process and staffing limitations, then a focus must be placed by NHS SWL ICB & the local authority on providing a range of appropriate and frequent supports that collaborate with and utilise voluntary organisation, for children as well as their parents/carers on the waiting list.

8. Feedback Mechanisms & A Culture of Listening

- We would recommend that the NHS SWL ICB integrates a tool into the Social Communication Difficulties Pathway for formal feedback mechanisms to develop a culture of listening, which considers and is responsive to the experiences of parents/carers and their children as vital to its design.

'I think other parents who maybe come after us, hopefully they're not going to go through this because I know it can break families. And that's the most important thing, that this whole waiting time is breaking families up' – Parent of a child on the Emerging Needs Pathway